

Findings from the Cancer Information Service 2003 User Survey

Final Report

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Prepared for:

Office of Communications
Cancer Information Service
National Cancer Institute
Bethesda, Maryland 20982

Prepared by:

WESTAT
1650 Research Boulevard
Rockville, Maryland 20850
(301) 251-1500

Matthews Media Group
6101 Executive Boulevard
Suite 300
Rockville, MD 20852

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For information about this report, please contact:

Madeline R. La Porta
Deputy Associate Director
Office of Cancer Information Service
National Cancer Institute, NIH
6116 Executive Boulevard, MSC 8322
Bethesda, Maryland, 20892-8322
301-594-8025
301-402-0555
laportam@mail.nih.gov

EXECUTIVE SUMMARY

Introduction

The Cancer Information Service (CIS) is a program of the National Cancer Institute (NCI), a Federal agency for cancer research. As a resource for information and education about cancer CIS helps people, particularly those who are medically underserved and who suffer from cancer health disparities, become active participants in their own health care. Through its network of regional offices, CIS serves the United States, Puerto Rico, the U.S. Virgin Islands, and the U.S. Associated Pacific Territories.

The three components of CIS—the Information Service, the Partnership Program, and the Research Initiative—help NCI to reach and respond to its many audiences with cancer information, and to learn how cancer communication can be strengthened. CIS has initiated an evaluation of all three program components and has contracted with Westat, an independent research organization, to conduct evaluation activities. This report presents findings from the evaluation of the Information Service, specifically on the results of the 2003 User Survey, a telephone survey of persons who contacted CIS that was conducted in late 2003 and early 2004.

Overview of the Information Service

The Information Service comprises a telephone service component that has operated since 1976; *LiveHelp*, an online messaging service that began in 2002; and an email service via www.cancer.gov. CIS staff has access to cancer information from NCI on a range of topics, including the most recent advances in cancer treatment. Persons seeking cancer information or resources can speak or Web chat with Information Specialists trained to explain medical information in easy-to-understand terms.

Survey Purpose and Background

The purpose of the 2003 User Survey was to serve as a baseline measure for assessing both process and impact measures. The key process indicators assessed were user satisfaction, specifically users' perceptions of the Information Specialists' knowledge level, trust in the information provided, likelihood of recommending the CIS to others, and whether or not users' expectations were met. Impact indicators included how users are affected by their contacts with Information Specialists in terms of their

increased knowledge and awareness, enhanced self-efficacy and communication skills, intentions to make positive behavioral changes, and—to a limited degree—actual behavioral change. Results will provide invaluable information to guide CIS in making improvements to the Service to better meet the public's cancer information needs.

This 10-minute survey was pretested in August 2003 and conducted in two phases from November 17 to December 21, 2003 and January 12 to March 14, 2004. Eligible persons were recruited by CIS Information Specialists¹. The sample included first-time users contacting a CIS regional contact center during the data collection period. The survey yielded 2,485 completed interviews. The CIS recruiting rate was 52% and Westat's weighted response rate for the completed interview was 75%. The weighted study response rate (CIS recruiting rate multiplied by the Westat response rate) was 39%.

Key Findings

Results from the User Survey indicate that persons who have contacted CIS for cancer- or tobacco-related information have derived many benefits from the interaction. Overall, CIS users were satisfied with their encounter and felt that their information needs were being met. These positive reports reflected many favorable impacts for users, including increased knowledge about cancer and/or tobacco issues, greater confidence in seeking additional cancer information and understanding the causes and risk factors for cancer, greater confidence in actively participating in treatment decisions, and positive intentions and/or efforts to make healthful behavioral changes. The following sections highlight key findings from this survey.

User Characteristics

- **Over half (57%) of all CIS users were contacting CIS for information about themselves; just under two-thirds (62%) of all users were either diagnosed with cancer themselves or seeking information for a friend or family member who had been diagnosed.** Of those calling for information for a friend or family member, 84% reported that this person had been diagnosed with cancer.
- **The most common reason for contacting the CIS was to obtain information about clinical trials (44%), and the most common cancer site/type mentioned was breast cancer (21%).** Users also contacted the CIS for information about tobacco (8%) and for help communicating with a health professional (23%).

¹ Eligible persons were defined as first-time users who contacted CIS by telephone or online using *LiveHelp*. Persons were age 18 or older, who were English speakers, and who were not health care professionals or members of the media. The study population was restricted to first-time users to maximize the likelihood that results reflect recent experience with CIS current protocols and quality assurance procedures. The study excluded persons who contacted CIS via email because demographic information is not collected for these users.

- **CIS users were typically white, female, and had attended either some college or had a college degree or higher level of education.** Seventy-five percent of those contacting CIS were female, and 75% were white. African Americans made up 11% of the contacts, all other races made up 8%, and 6% were persons of Hispanic origin. Sixty-seven percent of users had some college, were a college graduate or had a higher level of education, and 33% had a high school education or less than a high school education.
- **The primary mode of contacting CIS was via the telephone.** Ninety-seven percent of sampled users contacted the Service via the 1-800-4-CANCER or 1-877-44U-QUIT lines, and 8% reported contacting CIS through the *LiveHelp* service online. Five percent contacted CIS using both modes.

Users' Knowledge About Cancer and Tobacco

- **Nearly half of users reported they felt only somewhat knowledgeable about cancer and/or the harmful effects of tobacco prior to contacting CIS.** Whites, older people, and those with higher education levels felt more knowledgeable than other persons. Thirteen percent of users perceived themselves as very knowledgeable, 27% indicated they felt knowledgeable, and 14% felt not at all knowledgeable. College graduates were more likely than those with less education to report that they were very knowledgeable about cancer and/or tobacco issues (15% vs. 11% for at least some high school and some college).
- **Nearly three-quarters of users reported that CIS had increased their knowledge.** Persons with a personal relationship to cancer (i.e., users who have been diagnosed with cancer or are a friend or family member of someone diagnosed with cancer), Hispanics, younger people, and those with some college were more likely to report that CIS had increased their knowledge somewhat or a lot.
- **CIS effectively communicates information to those who self-reported low levels of knowledge prior to their CIS contact.** Users who reported being not at all knowledgeable prior to CIS contact were more likely than others to indicate that CIS increased their knowledge a lot (52% vs. 31% very knowledgeable, 31% knowledgeable, and 43% somewhat knowledgeable).
- **Nearly three-quarters (71%) of the persons who contacted CIS about their own tobacco use said that their contact with CIS changed their thinking about using tobacco.** African Americans and Hispanics were more likely than whites to report their thinking had changed (87% and 87% vs. 65%).
- **CIS actively disseminates clinical trials information.** Clinical trials information was disseminated to 60% of persons contacting CIS for cancer information; 47% of users requested information on clinical trials, and 13% received it at the discretion of the Information Specialist. Fifty-three percent of the 13% who received clinical trials information even though they did not request it said they were unaware of clinical trials prior to their CIS contact.

Self-Efficacy

- **CIS contact was responsible for increased confidence for each of the three self-efficacy measures.** Sixty-seven percent of all users reported that they felt more confident in their ability to seek information following their contact with CIS. In addition, 60% of users who indicated that they had been diagnosed with cancer and were contacting the Service for themselves reported feeling more confident in their ability to actively participate in their treatment decisions, compared to 39% of these users who reported no change in their level of confidence. Forty-five percent of users who did not have a personal relationship with cancer reported feeling more confident in their ability to understand the causes and risk factors for cancer.
- **Increased confidence to perform certain behaviors following CIS contact was influenced by several demographic characteristics.** Users who felt more confident in their ability to seek information following their CIS contact were more likely to be female, Hispanic, to have a personal relationship with cancer, and to have some college education. Those who felt more confident in their ability to understand the causes and risk factors for cancer tended to be persons under age 40, and Hispanics were more likely than whites to feel this way (54% vs. 43%).

Satisfaction with CIS

- **Overwhelmingly, CIS users were satisfied with the service they received, irrespective of whether they contacted CIS by telephone or online. Those with a personal relationship to cancer or calling on behalf of a friend or family member reported overall greater levels of satisfaction than those with no personal relationship cancer or those calling for themselves.** Sixty percent of users were very satisfied and another 35% said they were satisfied. Those who had contacted CIS for a friend or family member were more likely than those who had contacted CIS for themselves to say they were very satisfied (64% vs. 56%). In addition, users who were diagnosed with cancer or had a friend or family member who was diagnosed were more likely to report being very satisfied than those contacting CIS about someone not diagnosed (62% vs. 57%).
- **Overall, users who were very satisfied with CIS had higher education levels, were female, and were younger.** CIS users with some college (64%) and with a college degree (62%) were more likely to report being very satisfied compared to the 54% of users with a high school education or less who reported that level of satisfaction. Women were more likely than men to say they were very satisfied with the Service (62% vs. 53%). Level of satisfaction was also related to age. Sixty-four percent of users age 40 and under reported being very satisfied compared with 58% of users age 51–60 and 57% of users age 61 or older. In addition, whites were more likely than African Americans and all other races to say they were very satisfied (62% vs. 53% and 52%, respectively).
- **The three dimensions of satisfaction measured in this study resulted in consistently high levels of satisfaction.** Users reported on whether their expectations for the call were met, their perception of the Information Specialist's knowledge, and their level of trust in the information they received. Most users (89%) said their expectations for their

contact were met or exceeded, and about four-fifths (83%) said they had a high degree of trust in the information they received. Overwhelmingly, users (98%) said that they thought that the Information Specialist who handled their inquiry was knowledgeable, and a little over half (52%) said the specialist was very knowledgeable.

- **Several user characteristics influenced users' perceptions of three satisfaction dimensions measured in the survey.** Users who contacted CIS for a family member or friend were more likely to say the Service exceeded their expectations (34% vs. 26%), and that was also true for those who were diagnosed with cancer compared to those who were not (32% vs. 25%). Similar to results for overall levels of satisfaction, users who said their expectations were exceeded were more likely to be educated, female, and younger. Hispanics were more likely than whites to say their expectations were met (36% vs. 30%), and they were more likely than whites or African Americans to regard the Information Specialist they communicated with as very knowledgeable (63% vs. 53% and 51%). Level of trust was related to age, such that users age 40 and under were more likely to report that they trusted the information a lot (86%) compared with users age 51–60 (81%) and those 61 or older (81%).
- **Increased self-efficacy was related to overall satisfaction with CIS.** Among all CIS users, those who reported feeling more confident in their ability to seek more information were more likely to report that they were very satisfied with CIS overall, when compared with users who reported no change in their level of confidence on this issue (71% vs. 37%). A similar pattern holds true with regard to one's confidence in understanding the causes and risk factors for cancer and confidence in one's ability to actively participate in treatment decisions.
- **Almost all users reported they would recommend the Service to someone else and/or contact CIS again if they had additional questions.** Nearly all (96%) of users said they would recommend CIS in the future and/or that they would recontact CIS. Twenty-two percent of users had already suggested someone they know contact CIS by the time of their interview.

Intention and Behavior

- **Persons contacting CIS for themselves about either a cancer or tobacco issue regarded the information they received to be valuable in discussions with their doctors or other health professionals.** In all, 71% indicated that the information they received from CIS had resulted in positive intention or behavior change. For instance, 28% of users said they had discussed the information they received from CIS with a health professional by the time of the survey, and another 43% said they planned to have such a discussion. Of the 28% of users who had already discussed the information with a health professional, 56% said the information helped them a lot. Of the 29% who did not plan to discuss the information they received with a health professional, many simply said they did not perceive that need, while others were just confirming information they had received from their doctor and further discussion was not warranted. Hispanics (40%) were more likely than whites (28%) and African Americans (25%) to report having a conversation with their doctor or health professional by the time of their interview.
- **CIS was particularly effective among smokers contacting CIS for themselves in influencing positive intentions and behavioral changes for ways to quit or cut back on smoking.** Ninety-four percent of tobacco users reported that the suggestions from

CIS helped them to make a tobacco-related change in their lives. When asked about specific changes they had made following their contact with CIS, 14% reported that they had quit smoking, 35% had cut back, and 45% planned to quit or cut back in the future. Among those who reported already cutting back on smoking, nearly all (96%) reported that they planned to quit. Of these, 40% indicated that they had set a quit date.

- **CIS influenced both the intention and behaviors of users who either contacted CIS for clinical trials information or did not explicitly contact CIS for that type of information but received it through the course of the contact.** Of those contacting CIS for themselves and receiving clinical trials information, 39% reported that following their CIS contact they had inquired about their eligibility to participate in clinical trials. Of those who had not yet inquired about their eligibility, 83% indicated that they planned to do so. The findings varied by only one user characteristic; those not diagnosed with cancer were significantly more likely to report that they had inquired about their eligibility to participate in clinical trials following their CIS contact than were users who said they had been diagnosed with cancer (46% vs. 31%). This is likely due to the promotion of the National Lung Cancer Screening Trial (NLST), which required that eligible participants not be diagnosed with cancer. Fifty-two percent of those who were not diagnosed with cancer inquiring about their eligibility to participate in trials were contacting CIS for information about NLST.
- **Nearly half (49%) of users who contacted CIS for themselves and received information about clinical trials said their CIS contact had led them to seek more information about clinical trials.** Of these, persons age 40 and under were more likely than those ages 61 or older to seek additional information (57% vs. 45%). The remaining 51% who had not sought additional information about clinical trials were asked to report on their reasons for not seeking more information. While the responses varied greatly, the most common reason cited by respondents was that they did not have enough information, had not read the information they received, or were unaware of how to follow up after their CIS contact.

Conclusions

Overwhelmingly, persons who contacted CIS by telephone or the *LiveHelp* online service expressed satisfaction with the service they received. Higher levels of satisfaction were found among those with higher levels of education, females, persons age 40 or under, and whites. Most users said their expectations for their contact were met or exceeded and about four-fifths said they had a high degree of trust in the information they received. Overwhelmingly, users said that they thought that the Information Specialist who handled their inquiry was knowledgeable, and a little over half said the Information Specialist was very knowledgeable. Nearly all users said they would recommend CIS to someone else in the future, and an equal number said they would recontact the Service if they had other questions. Fewer persons with a high school education or less felt their expectations for the call had been met or exceeded and that the Information Specialist was very knowledgeable. It is possible the content being provided by CIS is more complex or the presentation more sophisticated than appropriate for less educated users resulting in their slightly lower reports of satisfaction.

CIS is an effective source of information and education about cancer. Persons who were more likely to believe their knowledge had increased a lot were younger (age 40 or under), had some college education, and had a personal relationship to cancer. Older users, those age 61 or older were more likely than younger users to report being very knowledgeable prior to contacting CIS. Seniors may already know the information that CIS was providing or felt less prepared to learn new information. Targeted efforts may be needed to effectively enhance CIS' educational reach to seniors.

CIS was successful in increasing users' confidence in their ability to seek more information about cancer or a tobacco-related issue, understand the causes and risk factors for cancer, and their ability to actively participate in decisions about their treatment following their CIS contact. CIS was most effective at increasing users' confidence to seek more information among persons with more education, females, younger persons (ages 40 and under), and Hispanics. Younger users were also more likely than the oldest users (61 or older) to say they were more confident about their understanding of the causes and risk factors for cancer, while the oldest users were more likely than all other age groups to say their confidence had stayed the same. While one-third of users said their confidence had not increased following their CIS contact, this does not necessarily indicate a lack of success on CIS' part. It is possible that those who reported no change in their confidence to perform these three behaviors may not have felt these actions to be salient or needed.

While few significant differences were found with regard to users' intentions and behaviors related to cancer or tobacco, results show that CIS positively influenced users' thoughts and actions. Many persons who received clinical trials information said they have discussed or plan to discuss this information with their health care professional. CIS appears to be particularly effective in reaching smokers who contact CIS for assistance in changing their use of tobacco. Most smokers reported that following their contact, they either planned to quit or cut back on smoking, had already cutback, or had quit altogether. A little over one-third of persons who received information about clinical trials said that they followed up to inquire about their eligibility to participate in a trial and four-fifths of those who had not yet inquired about their eligibility intended to do so. Still, a small group of users who sought clinical trials information said they did not plan to seek additional information, did not have enough information, had not yet read the information they received, or were unaware of how to follow up after their CIS contact.

CIS' effect on users' knowledge, confidence, intention or actions taken to perform specific behaviors, and their satisfaction with the service provided by CIS was fairly consistent across racial and ethnic groups, although a few differences were noted. Whites were more likely than African Americans to say they were very satisfied. On several dimensions, Hispanics users were more positive about CIS than those of other racial/ethnic groups. Given that CIS has not undertaken concerted efforts to

specifically target the Hispanic community as cancer information seekers, the extent of positive responses is notable.

CIS succeeded in meeting the information needs of its youngest users (age 40 and under). They were more likely than seniors (age 61 and older) to say that their contact had increased their knowledge a lot, and that they felt more confident in their ability to seek additional cancer or tobacco information. Younger users were also more likely than older users to report they were very satisfied, that their expectations for their contact had been exceeded, and that the Information Specialist who assisted them was very knowledgeable. More assistance may be needed for older adults who already felt knowledgeable prior to their contact and did not think that CIS had increased their knowledge or provided them with greater confidence or understanding. Future research could assess the information needs of this group.

Level of education was found to influence many study outcomes of interest. Broadly speaking, better educated users reported more positive outcomes on a range of satisfaction outcomes. On the other hand, persons with a high school education or less were more likely to report being dissatisfied with their CIS contact. Although satisfaction levels were very high and many positive outcomes were found in this study overall, more efforts may be needed to target persons with lower education levels to effectively meet their information needs and empower them to become more confident in adopting healthful behavioral changes.

Differences were found among persons with and without a personal relationship to cancer. CIS was effective in providing information to users with a personal relationship to cancer. In comparison to persons with no relationship to cancer, cancer patients or persons contacting CIS about a friend or family member with cancer said CIS had significantly increased their knowledge and that they had used the information they received in their CIS contact to have a conversation with their doctor or another health professional. They were more confident in their ability to seek cancer information and more likely to report being very satisfied following their CIS contact. Persons with no relationship to cancer reported less satisfaction, lower levels of increased knowledge, and less confidence in seeking more cancer information. Persons not affected by cancer may be less experienced health information seekers and may be less sophisticated in formulating questions or understanding the information they received. In turn, this may contribute to their lowered sense of confidence.

Results from the 2003 User Survey illustrate that persons who have contacted CIS for cancer- or tobacco-related information derived many benefits from the interaction. Overall, CIS users were satisfied with their encounter and felt that their information needs were being met. These positive reports reflected many favorable impacts for users including increased knowledge about cancer and/or

tobacco issues, greater confidence in seeking additional cancer information, greater understanding of the causes and risk factors for cancer, greater confidence in their ability to actively participate in treatment decisions, and positive intentions and/or efforts to make healthful behavioral changes. Patterns were found identifying areas of strengths and possible areas for improvements from which CIS and its users could benefit. Additional research could be conducted to determine the sources and reasons for differences found among CIS users with respect to their experiences in utilizing CIS' telephone and online services.

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1. INTRODUCTION AND BACKGROUND

1.1 Overview of the Cancer Information Service

The Cancer Information Service (CIS) is a program of the National Cancer Institute (NCI), a federal agency for cancer research. As a resource for information and education about cancer, CIS helps people, particularly those who are medically underserved and who suffer from cancer health disparities, become active participants in their own health care. Through its network of regional offices, CIS serves the United States, Puerto Rico, the U.S. Virgin Islands, and the U.S. Associated Pacific Territories.

For more than 25 years, CIS has provided cancer information to patients and families, the public, and health professionals by

- interacting with people one on one;
- working with organizations;
- participating in research efforts to find the best ways to help people adopt healthier behaviors;
- providing access to NCI information over the Internet; and
- providing smoking cessation assistance and supporting regional tobacco control efforts.

The work of CIS is organized into three components—the Information Service, the Partnership Program, and the Research Initiative.

The Information Service. CIS disseminates cancer information and resources from NCI through a variety of modes including a toll-free telephone service (1-800-4-CANCER), NCI Smoking Quit Line (1-877-44U-QUIT), *LiveHelp*, an online instant message service, and an email service via www.cancer.gov. Users can access recorded information or order publications by telephone or communicate with a trained CIS Information Specialist both online and by telephone on a broad range of cancer topics.

Through the CIS Information Service, CIS users receive:

- answers to their questions about cancer, including ways to prevent cancer, symptoms and risks, diagnosis, current treatments, and research studies;

- written materials from the NCI;
- referrals to clinical trials and cancer-related services, such as treatment centers, mammography facilities, or other cancer organizations; and
- assistance in quitting smoking from Information Specialists trained in smoking cessation counseling.

The Partnership Program. Through its Partnership Program, CIS collaborates with established national, state, and regional organizations to provide cancer information to minority and medically underserved audiences. Partnership Program staff provide assistance to organizations developing programs that focus on breast and cervical cancer, clinical trials, tobacco control, and cancer awareness for special populations. To reach those in need, CIS:

- helps bring cancer information to people who may have difficulty seeking information because of educational, financial, cultural, or language barriers;
- provides expertise to organizations to help strengthen their ability to inform people they serve about cancer; and
- links organizations with similar goals and helps them plan and evaluate programs, develop coalitions, conduct training on cancer-related topics, and use NCI resources.

The Research Initiative. CIS plays a role in research by studying the most effective ways to communicate with people about healthy lifestyles; health risks; and options for preventing, diagnosing, and treating cancer. Results from these research studies can be applied to improving the way CIS communicates about cancer and can help other programs communicate more effectively.

CIS has initiated a comprehensive evaluation of its three components as described in detail in the *Comprehensive Evaluation Plan for the Cancer Information Service*. Each component is the subject of a separate evaluation designed specifically to measure appropriate process and impact questions. This report presents findings from the evaluation of the Information Service, specifically on the results of the 2003 User Survey, a telephone survey of persons who contacted CIS, conducted in late 2003 and early 2004. The User Survey was designed to measure user satisfaction with CIS services and assess users' perceived knowledge about cancer, self-efficacy in making treatment decisions, and behavioral intention and behavior related to cancer prevention and/or treatment.

1.2 Overview of the Information Service

The telephone service component of the Information Service has operated since 1976 and is the CIS' longest standing and most developed program component. CIS staff have access to cancer information from NCI on a range of topics, including the most recent advances in cancer treatment. Through the CIS toll-free telephone service (1-800-4-CANCER), callers seeking cancer information or resources can speak with staff trained to explain medical information in easy-to-understand terms. Specialists provide service 9:00 a.m. to 4:30 p.m., Monday through Friday, in English, Spanish, or TTY for individuals who are deaf or hearing impaired. Specialists also provide smoking cessation information and support to smokers through NCI's Smoking Quit Line at 1-877-44U-QUIT. Recorded information on both numbers is available 24 hours a day, 7 days a week.

CIS routinely gathers information about the type of persons calling their telephone service. Data show that users tend primarily to be middle-income white women. Call volume to the telephone lines peaked in 1994 and has been declining in the last 9 years. Results from the 2003 User Survey are intended to inform the development of a promotion plan to increase the use of CIS telephone and online services especially by minorities and men.

In 2002, CIS launched a new online service, *LiveHelp*, to provide answers to questions about cancer and help in navigating Cancer.gov, the NCI's web site. This service, available Monday through Friday from 9:00 a.m. to 10:00 p.m. eastern standard time, is intended to provide another confidential point of access for the public to obtain cancer information and resources.

Recently, CIS has begun providing services to CIS users via email through the www.cancer.gov web site. Email users were not included in the 2003 User Survey, however, because demographic data and information about their CIS contact needed for analyzing the survey data is not collected for these users.

The Information Service has conducted numerous evaluation activities to assess service delivery and performance excellence. Many systems (e.g., staff management systems, training and quality standards) have been developed to manage the service and document performance. Periodic surveys of persons calling CIS for cancer information were conducted in the past (1976, 1984, and 1996) and measured satisfaction with the Service as well as a wide range of effects related to callers' intentions and behavioral changes following their discussion with CIS.

1.3 Survey Purpose and Background

In accordance with the *Comprehensive Plan for Evaluation of the CIS*, the 2003 User Survey is intended to serve as a baseline measure for assessing both process and impact measures. This survey will be repeated in 2006 and will continue on a regular basis every 3 years. The key process indicator to be assessed is user satisfaction, specifically users' perceptions of the Information Specialist's knowledge level, trust in the information provided, likelihood of recommending the CIS to others, and whether or not users' expectations were met. Process evaluation results will inform CIS of strengths and weaknesses in the implementation of the services provided by CIS. Process data will also provide a context for understanding the influence of the Service on users. Thus, if many users report lower satisfaction levels than anticipated and that their contact with CIS had *not* led them to plan to quit or cut back on their tobacco use, the results from the process evaluation may help explain these findings.

The survey documents how users are affected by their contacts with Information Specialists in terms of their increased knowledge and awareness, enhanced self-efficacy and communication skills, intentions to make positive behavioral changes, and—to a limited degree—actual behavior change. It is expected that after contacting the CIS, users should feel more knowledgeable about the specific subjects of inquiry and have increased awareness of cancer in general. Self-efficacy, a key impact indicator, refers to users' confidence in their ability to perform healthful behaviors. For example, users are expected to have increased confidence in their ability to communicate with health care professionals, to better understand the causes of cancer or potential risk factors for cancer, and to actively participate in treatment decisions. As a result of their contact with CIS, users should also report positive behavioral intentions or changes with regard to reducing or eliminating their tobacco use, discussing information they learned from CIS with their own health professionals, and determining eligibility for enrolling in clinical trials, as appropriate.

Results from the 2003 User Survey will provide invaluable guidance to CIS for making improvements to better meet the public's cancer information needs. For example, if users report their knowledge about cancer has increased, yet their confidence in their ability to communicate with a health professional has stayed the same, then Information Specialists could be trained and directed to spend more time with CIS users on skills or strategies for seeking health information.

2. METHOD

The 2003 User Survey was designed as a 10-minute telephone survey with a national sample of 2,500 users stratified by type of user (e.g., diagnosed with cancer or not; contacting for self or family member/friend), reason for contact, cancer site, mode of CIS contact (telephone or *LiveHelp*), and several demographic characteristics. Eligible persons were defined as first-time users who contacted CIS by telephone or online using *LiveHelp*. Persons were age 18 or older, who were English speakers, and who were not health care professionals or members of the media. The study population was restricted to first-time users to maximize the likelihood that results reflect recent experience with CIS current protocols and quality assurance procedures. The study excluded persons who contacted CIS via email because demographic information is not collected for these users. Potential respondents were recruited by CIS and contacted by trained Westat interviewers within 30 days of the contact with CIS. The following sections describe the methodology employed to design and conduct the survey and analyze and present results.

2.1 Questionnaire Design

Westat staff and NCI's Project Office Evaluation Team collaborated on designing a questionnaire to address the key process and impact indicators discussed in Section 1.3. The first step entailed reviewing the 1996 survey instrument and mapping the questionnaire items to the key process and impact indicators outlined in the CIS evaluation plan. While the process measures for overall user satisfaction (e.g., Information Specialist was knowledgeable, information provided was trustworthy) included in the 1996 survey were still appropriate, few of the remaining items were of continued interest or relevance to CIS. Thus, major questionnaire redesign was warranted for several reasons. First, new questionnaire items were developed to assess the broader result of CIS contacts on impact indicators not included in previous surveys. Second, questions were added to ascertain type of user and mode of contact with CIS due to CIS interest in such an analysis. Finally, the questionnaire was designed to focus on the three primary reasons for contact of particular interest to CIS, accessing information about tobacco, inquiring about clinical trials, and seeking assistance in communicating with health care professionals.

Eight pretests were conducted with individuals who recently contacted CIS using the 1-800-4-CANCER telephone number or *LiveHelp* services. CIS recruited individuals from 3 of their 14 regional call centers, and efforts were made to obtain a mix of callers with regard to their reason for contact to ensure that all portions of the questionnaire could be appropriately tested. Using a recruiting script, Information Specialists informed prospective participants that their participation was voluntary and

confidential and would not affect the service they receive through CIS. The average interview length was 16 minutes. In addition to responding to survey questions, pretest respondents were asked to comment on whether the questionnaire items made sense to them, if they considered them to be relevant, their reasoning for how they answered certain items, and whether any items were too sensitive or would make people feel uncomfortable. Results were summarized and presented in a report to CIS. The questionnaire was then revised to address the pretest results and incorporate further comments from CIS.

The final questionnaire consisted of 59 items, 57 with close-ended responses and two open-ended questions (see Appendix A). The survey was designed such that a core set of questions on the subject of the contact (e.g., for self or family member), reasons for contact, satisfaction domains, and other cancer organizations contacted were asked of all respondents. Those respondents who indicated they contacted CIS specifically for information about tobacco, clinical trials, or communicating with a health care professional or any combination of these topics were asked a series of questions relevant to the topics they identified.

The survey was programmed using interactive computer-assisted telephone interviewing (CATI) technology. This method was advantageous because of the relatively large number of interviews to be conducted and NCI's desire to incorporate more complex routings through the questionnaire than is allowable in a paper-and-pencil format. Using the CATI format was also intended to prevent out-of-range responses and increase the expediency of data processing and analysis. The instrument was tested online by Westat and CIS staff prior to the survey launch.

2.2 Recruiting and Data Collection Schedule

Timing was an important factor in designing the recruiting and data collection schedule. The survey was slated to be launched in late fall 2003. Due to the undesirability of interviewing during busy holiday periods at the end of the year, CIS decided to collect data in two phases. Phase I recruiting and data collection was scheduled from November 3 through December 22, 2003. Phase II was conducted between December 29, 2003, and March 15, 2004 (see Exhibit 1).

Early in the planning process, it was determined that a recruiting and sampling design was needed that limited the time period between contact with CIS for information and Westat calls to potential respondents for interviews. There was some concern that too much lag time might result in diminished respondent recall of their CIS contact. A rolling recruiting and data collection schedule was designed. Users were recruited, sampled, and interviewed in 12 separate waves on an overlapping basis. Westat interviewers planned to contact each sampled potential respondent for an interview during a defined

2-week period for each wave, after which time the case expired if an interview had not been completed. In this way, new potential respondents were continually being recruited and contacted for interviews throughout the data collection periods while ensuring that contact by a Westat interviewer was always made within in 4 weeks of users' initial CIS contact.

Exhibit 1.—CIS recruiting and Westat data collection schedule

Sample	CIS recruitment	Westat data collection
PHASE I		
Wave 1*	November 3–7	November 17–November 30
Wave 2*	November 10–14	November 24–December 7
Wave 3	November 17–21	December 1–14
Wave 4	November 24–26**	December 8–21
PHASE II		
Wave 5	December 29–31, January 2**	January 12–25
Wave 6	January 5–9	January 19–February 1
Wave 7	January 12–16	January 26–February 8
Wave 8	January 19–23	February 2–15
Wave 9	January 26–30	February 9–22
Wave 10*	February 2–6	February 16–29
Wave 11*	February 9–13	February 23–March 7
Wave 12	February 16–20	March 1–14

*Includes potential respondents from the New England regional call center.

** Shortened recruiting period due to federal holiday.

2.3 CIS Recruiting and Transfer of Electronic Contact Record Form Data

All survey participants were first-time CIS users who contacted CIS by telephone or online during the Phase I and II recruiting periods. CIS recruited survey participants to maximize response rates. Study designers thought that if participants were invited to participate in the survey by the Information Specialist with whom they spoke during their CIS contact, they likely would be more amenable to participating in a follow-up telephone interview. Westat supplied CIS with a script to ensure consistency in recruiting (see Appendix B). To recruit potential participants in accordance with Office of Management and Budget (OMB) regulations, it was planned that CIS would randomly collect demographic information from 50 percent of first-time users.² Demographic and contact information was obtained from any of those persons who agreed to participate in the study. However, the active recruiting from CIS was such that if an eligible user declined to participate in the survey or refused to provide demographic information, he/she was retained in the sampling frame of all first-time users but excluded from the population from which Westat drew the study sample, and another user was drawn as a replacement. This resulted in CIS sampling a higher percentage, about 59 percent, of first-time users than was planned. A more detailed explanation of the sampling design is provided in Section 2.4.

²Typically, CIS only collects demographic information from 25 percent of user contacts to comply with OMB regulations. However, during special data collection periods, CIS can collect this information from as many as 50 percent of users. The OMB number for CIS demographics collection is 0925-0208.

The original plan required CIS Information Specialists to recruit potential respondents on a weekly basis for 12 weeks. During survey planning, however, Westat learned the New England call center was conducting a regional survey that overlapped with the User Survey data collection period. To decrease the potential burden on users, the call center agreed to suspend their data collection for 2 weeks in November 2003 and another 2 weeks in February 2004 to allow data to be collected for the User Survey. Thus, potential respondents from the New England region were recruited during only 4 of the planned 12 weeks.

To recruit potential participants for this study, CIS appended an existing electronic form to collect comprehensive information during each user contact. The form used by CIS to input data into the database is an Electronic Contact Report Form (ECRF) and is used to collect information such as the type of user, subject of interaction, CIS resources used, CIS response, and cancer site (see Appendix C). Demographic characteristics are gathered from about 25 percent of users. To automate the User Survey recruiting process, CIS added several fields to the ECRF to track whether the 50 percent of first-time users who were randomly selected to provide demographic information had agreed to participate in the survey and to record their name and telephone number. During recruiting, and in accordance with CIS call-back policies, Information Specialists also indicated on the ECRF whether potential respondents would allow Westat interviewers to explicitly mention the National Cancer Institute and disclose the nature of the call when making contact.

2.4 Sample Design and Selection

2.4.1 Sample Design

CIS recruiting data were transferred from CIS, and potential respondents were sampled by Westat on a weekly basis during the recruiting and data collection phases. The Monday following each week of data collection, CIS provided Westat with an electronic export file for sampling containing names and telephone numbers for all potential respondents along with their corresponding ECRF data, including demographic information. The original sampling plan called for Westat to draw an equal sample from each of the 12 weekly export files to be provided by CIS for a total sample of 3,336 potential respondents. With a goal of 2,500 completed interviews, and an assumed 75 percent overall response rate, it was estimated that each wave would require Westat interviewers to call 278 potential respondents to obtain 208 completed interviews. Since the New England call center was included in only 4 of the 12 weeks, the plan necessitated increasing the sample during those weeks and lowering it during the remaining weeks to obtain an appropriate sample. Therefore, in the weeks that included the New England cases, 318 users would be sampled, and in the remaining 8 weeks the sample was to be 258.

Three subgroups of users, (patients, those contacting for tobacco information, and minorities) were of particular interest to CIS. Westat estimated the proportion of these groups in the completed cases to ensure that reliable estimates would be obtained for each subgroup and determined that sufficient reliability for patients and minorities was achievable without oversampling. Tobacco information users were found to represent a small subset of callers; triple oversampling was planned to obtain a large enough subgroup for reliable analysis.

The sample frame was stratified by a range of NCI-approved criteria to help ensure adequate representation of key user characteristics. The sort variables, in order of which sorts were performed, were user type (e.g., patient, family member/friend), race/ethnicity, sex, and call center. If any sampled cases were missing values for these four sort variables, the missing variables were imputed to the largest group within that category before sampling.

Some eligible potential respondents, first-time users who refused to provide demographic information, were included in the weekly export file sent to Westat by CIS but excluded from the sampling frame. Also, if an individual was considered to be too distressed or ill to be asked for demographic information or to participate in the User Survey, CIS Information Specialists had the option of designating these users as not to be contacted. While these people were not included in the sampling frame, they were counted as nonrespondents for the recruitment stage of sample selection and included in the CIS response rate calculations.

Westat statisticians reviewed the export file for case eligibility before drawing the sample for each of the 12 waves. Occasionally, some cases included in the export files were excluded. Recruited users who were ineligible for the sample included non-English speakers, those under age 18, health professionals or media representatives, and users who had contacted the Service previously.

2.4.2 Sampling Rates

The first stage of sampling consisted of CIS recruitment of eligible cases. Overall, the CIS sampling rate averaged 59 percent, higher than the original half-sample that was planned. It appears that in some instances, a replacement was drawn for ineligible cases, increasing the overall CIS sample rate. The Westat sampling rate was determined by the estimated Westat response rate and the goal for the number of completed interviews. Table 1 shows the actual CIS and Westat sampling rates of 59 percent and 50 percent, respectively, and the overall sampling rate of 30 percent, calculated by multiplying the CIS and Westat sampling rates.

Table 1.—CIS sampling rates, total and by subgroup: 2004

Sampling rate	CIS	Westat	Overall
Total	0.59	0.50	0.30
Subgroup			
Tobacco	0.57	1.00	0.57
<i>LiveHelp</i>	0.62	0.79	0.49
New England call center	0.15	0.74	0.11
All others	0.58	0.46	0.27

Westat oversampled for some subgroups, and their sampling rates are shown in Table 1. A triple oversample of tobacco users was planned. However, a lower number of tobacco users were recruited for the study than was anticipated, so tobacco users were sampled with certainty.³

Callers to the New England call center also required a differential sampling rate. As shown in Exhibit 1 in Section 2.2., the New England call center was included only in the first two recruitment waves in Phase I and Waves 10 and 11 in Phase II. Because the number of New England callers that were recruited was low, Westat sampled all of the New England region users with certainty in Waves 10 and 11.

LiveHelp users were another oversampled subgroup. *LiveHelp* users were recruited differently in that those who agreed to participate in the survey were asked to provide contact and demographic information over the Internet within a 24-hour period. In many cases, *LiveHelp* users agreed to participate in the survey when they were on line with an Information Specialist but did not follow up by providing the necessary contact and demographic information. As a result, fewer *LiveHelp* users were included in the sampling frame than anticipated. To adjust for the low recruiting rates, *LiveHelp* users were sampled with certainty beginning in Wave 7, which raised their sampling rate.

During the recruiting and data collection period, the sample size was adjusted as needed to maintain as consistent a sampling rate as possible for each wave. For instance, Wave 5 had an unusually small sampling frame because fewer contacts were made to CIS during the week following Christmas, and hence fewer potential participants were recruited. In an effort to maintain a consistent sampling rate, the sample size for this wave was lowered to 212 from 258. Westat statisticians continued to monitor the sample size in subsequent weeks. The size of the sampling frames in Waves 11 and 12 permitted sampling of more cases to make up for the lowered sample in Wave 5.

³ Users who were sampled with certainty were those whose probability of being selected in the sample was 1 because of their lower than expected representation in the sampling frame. Thus, all eligible users in these subgroups were included in the sample.

2.5 Data Collection

2.5.1 Interviewer Training

An interviewer training was conducted at Westat's Frederick, Maryland, Telephone Research Center (TRC) on Saturday, November 15, 2003, led by the TRC manager for the User Survey. Fourteen interviewers were trained; all had previous experience in conducting interviews for Westat telephone research studies.

The training session, which lasted approximately 8 hours, consisted of three components: 1) an overview of the Cancer Information Service and survey purpose; 2) review of interviewing techniques and procedures, and 3) study-specific training for administering the survey. The first component was presented by an NCI Project Officer, and included an interactive discussion of common and unusual inquiries that CIS receives. Because trainees already had a wealth of interviewing experience, little time was needed to review standard procedures and emphasis was placed on changes in procedure specific to this study. Most of the training focused on preparing interviewers for the great variation in reasons why people contact CIS and how to sensitively guide interviews to completion with persons who might be older, ill, or distressed. Three interactive lecture scripts presented several scenarios for various types of users and reasons why they contact CIS to familiarize interviewers with all portions of the questionnaire. Trainees were provided with written information on handling sensitive situations, frequently asked questions, definitions of clinical trials, and names of trials likely to be active during the User Survey data collection. Additional study-specific training included:

- the importance of not divulging the purpose of the call unless speaking to the respondent to ensure the confidentiality of the respondent's health status;
- the importance of not providing personal opinions, support, or information to respondents and directing respondents in need of assistance to recontact the CIS;
- role-playing sessions in which participants practiced interviewing each other; and
- a question-and-answer session.

A copy of study-specific training materials can be found in Appendix D.

2.5.2 Survey Implementation and Quality Control

The 2003 User Survey was conducted between November 17, 2003, and March 14, 2004. Data collection was conducted in two phases as discussed in Section 2.2.

Westat contacted potential respondents multiple times on different days and at varying times of day during the 2-week data collection period for each wave. Due to concerns about potentially contacting persons who were ill or distraught, no refusal conversion was conducted for this study.

Westat implemented procedures to ensure that the confidentiality of potential respondents' health status was maintained and to provide full disclosure about the study. Interviewers were instructed to leave answering machine messages only if the individual had indicated this was acceptable when recruited by the CIS Information Specialist. Likewise, if an interviewer reached someone other than the respondent or an answering machine, he/she mentioned that the call was made on behalf of the National Cancer Institute only if the respondent had previously agreed that this was acceptable. Copies of the scripts are included in Appendix B. If an interviewer contacted a respondent who requested more information about the study, Westat collected name and address information and sent a detailed letter about the study sponsor, purpose of the study, and contact information for Westat and NCI staff to verify the legitimacy of the study (see Appendix E). Westat also provided potential respondents with a toll-free number that individuals could call at their convenience to set up an appointment for an interview.

Quality control measures were applied throughout the data collection process. Interviewers were monitored closely by a supervisor in the first week of data collection, and any suggestions for improvement were discussed with the interviewer immediately afterwards. During this time period, the NCI Project Officers, the TRC manager, and project research staff participated in monitoring sessions to ensure that the questionnaire was being administered accurately and that items were understood by respondents. In subsequent weeks, monitoring continued on a frequent basis by TRC supervisors and experienced project staff. Interviews were monitored using Telephony equipment, which allowed observers to monitor interviews unobtrusively by both listening to the telephone interview and watching the key strokes made by interviewers on a computer screen. The overall monitoring rate was 12 percent. Problem cases (e.g., nonlocatable or inappropriate respondents within the sample) were reviewed each week, and decisions were made about how to resolve them on a case-by-case basis. Detailed status reports were provided to the project director weekly. These reports provided specific information on the number of completed interviews, refusals, ineligible, nonlocatables, and maximum calls.

One issue arose in the first 2 days of interviewing that required remedial measures. Respondents were asked at the beginning of the interview if they had contacted the CIS during the last 30

days, and a higher than expected number of users said they had not contacted the CIS at all or had not done so in the previous 30 days. A consistency check was instituted during the first week of interviewing. Since names and telephone numbers could not have been obtained for these individuals unless they had contacted CIS during the User Survey recruiting period, interviewers were instructed to probe to see if respondents could recall contacting CIS either by telephone or online. As a result, fewer cases were coded as ineligible in the ensuing weeks of data collection. A copy of the consistency check that was used to determine respondent eligibility is included in Appendix F.

In early January, Westat and NCI Project Officers met to discuss the ongoing status of the recruiting and data collection procedures. There was some concern because CIS recruiting rates were approximately 20 percent lower than for the previous User Survey conducted in 1996 using a similar recruiting method. After discussing possible options for increasing recruiting rates, Westat and CIS agreed to revise the recruiting script to shorten and simplify the language and reorder questions for a more natural flow. These procedures were instituted beginning with Wave 9. Nevertheless, only a very small increase in recruiting rates was realized.

2.6 Weighting

The User Survey was designed to provide estimates for all eligible persons. Accordingly, weights were developed so the sample would be representative of that population. First, weights were developed to account for respondents having different probabilities of being selected for the survey. Users had two opportunities to be selected, once when they were sampled by CIS and again when they were sampled by Westat. Thus, two stages of weighting were applied. The CIS probability of selection was the number of eligible sampled users divided by the total number of eligible users (except for the New England call center, which was weighted separately). The Westat probability of selection was the sampling rate used for systematic sampling. Thus, the base weight for each user was the inverse of the user's selection probability at each level of selection; it was then adjusted for nonresponse. Final weights were calculated separately for each wave for all of the call centers taken together, except for New England.

The New England call center was handled differently in the weighting process because it sampled users for only 4 of the 12 weeks of data collection. For New England users, the base weight was calculated to be the number of eligible New England users in the total 12-week data collection period divided by the number of New England users in the Westat sample for the 4 weeks. In this way, the sample for New England was weighted to be representative of all callers to that center.

The next stage in the weighting process was a raking procedure that permitted Westat statisticians to control estimates to known totals on important characteristics while adjusting for the two levels of nonresponse. Raking is a procedure in which iterative adjustments are made to sample weights so that the sample more closely matches known population characteristics on some set of dimensions. These dimensions are called controls. For example, suppose only one type of user and call center were to be used for controls. First, weights would be adjusted so that the estimate from the sample would agree exactly with the number of persons by type of user across all weeks from which the sample was being selected. The resulting weights would then be adjusted again so that the estimate from the sample would agree exactly with the number of persons by call center across all weeks. This last weight adjustment would result in sample estimates that no longer exactly agreed with type of user totals. Thus, a weight adjustment would be repeated by user type. The iteration of weight adjustments by type of user and call center continued in this manner until sample estimates agreed closely to both sets of controls.

Raking for the User Survey involved several controls. For instance, type of user, call center, and the reason for calling was known for nearly all users, and those variables were used in raking.⁴ The type of cancer about which the user called was also known; however, since there were so many types of cancer categories and there was no meaningful way of collapsing them, the percentage of users calling about each type of cancer was too small to use for raking.

Other important characteristics for raking were not known for all users, because that information is not routinely collected by CIS in all contacts. Therefore, controls for race/ethnicity, sex, education, and age were based on the CIS sample for those users who gave contact information. Sample variables are not generally used in a raking procedure; however, since the CIS sample was such a large percentage of the study population, the sampling error was estimated to be very small. Controlling to sample estimates for these demographic variables reduced sampling errors nearly as much as it would have had the demographic information been known for the full population. A hot-deck imputation procedure⁵ based on the type of user and cancer site was used to impute the missing data for those who did not give demographic information. The totals after imputation were multiplied by the CIS sampling rate to estimate the population totals, and the sample was then raked to those totals.

⁴ These variables were missing for less than 1 percent of users.

⁵ G. Kalton and D. Kaspryck, The treatment of missing survey data. *Survey Methodology*, 12 (1986): 1-16.

2.7 Response Rates

Interviews were completed with 2,485 CIS users. Table 2 shows the sample, planned interviews, percent of planned interviews completed, and unweighted and weighted completed interviews for each wave of data collection.

Table 2.—Number of users included in sample and planned and completed number of interviews, by wave: 2004

Wave	Westat sample	Planned number of interviews	Unweighted number of interviews completed	Percent of planned interviews completed	Weighted number of completed interviews
Total.....	3,336	2,500	2,485	99	24,542
1.....	318	238	201	85	2,241
2.....	318	238	251	106	2,396
3.....	258	193	202	105	2,176
4.....	258	193	199	103	1,163
5.....	212	159	169	106	1,056
6.....	258	193	189	98	2,268
7.....	258	193	185	96	2,074
8.....	258	193	203	105	2,226
9.....	258	193	188	97	2,249
10.....	318	238	237	100	2,549
11.....	334	250	239	96	2,304
12.....	288	216	222	103	1,840

NOTE: Planned number of interviews may not add to total because of rounding.

Table 3 shows response rates for the CIS and Westat samples. Response rates were defined as the number of eligible respondents divided by the total number of sampled users in each wave. For the CIS sample, ineligible users were defined as users under the age of 18; non-English speakers; users who were not first-time callers; health professionals, members of the media, or other professionals; and users in the New England region during the weeks that this region was not sampled. In one case, a potential respondent passed away after contacting CIS but prior to when a Westat interview recontacted him for an interview and this case was subsequently coded as ineligible.

Both weighted and unweighted response rates are shown for the Westat sample. The weighted response rates were based on base weights that reflect the probabilities of selection. The weighted and unweighted rates are the same for the CIS sample because base the weight is the same for all sampled users.

Table 3.—CIS User Survey weighted and unweighted response rates, by wave: 2004

Wave	CIS response rate	Westat unweighted response rate	Inclusive unweighted response rate	Westat weighted response rate	Inclusive weighted response rate
1	53.99%	63.41%	34.23%	64.37%	34.75%
2	50.08	79.18	39.66	79.80	39.97
3	48.71	78.91	38.44	78.46	38.22
4	49.48	78.04	38.62	77.81	38.50
5	52.64	79.72	41.97	79.85	42.04
6	49.44	73.26	36.22	76.10	37.62
7	49.63	71.71	35.59	71.02	35.24
8	52.93	78.68	41.65	78.38	41.49
9	55.33	72.87	40.32	73.58	40.71
10	52.01	75.00	39.01	74.47	38.73
11	53.02	71.56	37.94	71.33	37.82
12	51.74	77.35	40.03	77.57	40.14
Overall	51.62	74.71	38.57	74.64	38.53

In a survey in which a subgroup that is sampled at a higher or lower rate has a very different response rate, there can be a substantial difference between weighted and unweighted response rates. However, there is little difference for this survey.

2.8 Estimating Standard Errors

When data are collected in a complex sample survey, there is often no easy way to produce approximately unbiased and design-consistent estimates of standard errors. The estimated standard errors of survey statistics, including means and proportions, using standard statistical packages such as SAS or SPSS are inappropriate and usually produce underestimates. The sampling procedure for the CIS survey, while not complex, did result in varying probabilities of selection among users. Both this and raking to control totals result in differential weights that ought to be accounted for in the standard error estimates.

A class of techniques called *replication methods* provides a general method of estimating standard errors for the type of designs and weighting procedures usually encountered in practice. The basic idea behind the replication approach is to select subsamples repeatedly from the whole sample, calculate the statistic of interest for each of these subsamples, and then use the variability among these subsamples to estimate the standard error of the full sample statistics. The subsamples are called *replicates*, and the statistics calculated from these replicates are called *replicate estimates*.

There are different ways of creating subsamples from the full sample. For this survey, replicate weights were created using the delete-one jackknife replication method. In the jackknife replication method, replicates are formed by deleting a single subset at a time, and the weights for other subsets increased to account for the deletion. Nine replicates were created within each week's sample, where the weeks were treated as strata.

2.9 Presentation of Results

Analyses for this report were based on weighted data from 2,485 completed interviews. However, as noted above, to streamline the survey and reduce respondent burden, series of survey questions were designed to be asked of selected respondents based upon the reason for their calls. For example, only individuals who said they contacted CIS about clinical trials or said that they received information about clinical trials during their contact were asked questions related to clinical trials. And, in some cases, questions that were relevant to some user types but not others were asked only of those for whom they were appropriate. For example, only respondents who called for themselves and were diagnosed with cancer were asked about changes in their confidence with regard to actively participating in treatment decisions. Therefore, some analyses were conducted on weighted data from a subset of respondents. Whenever data are presented for a subset of respondents, rather than the whole sample, that fact is specified in the text and noted in the table title along with the appropriate number of weighted cases.

The following independent variables were used for analyses:

Variables obtained from ECRF:

- Level of education (high school or less, some college, college graduate or higher)
- Sex (male and female)
- Age (40 and younger, 41-50, 51-60, 61 and older)⁶
- Race/ethnicity (white, non-Hispanic; African American, non-Hispanic; Hispanic; all other races)⁷
- Cancer site

Variables obtained from the User Survey:

- Diagnosis (user diagnosed with cancer or not diagnosed)
- User type (contacting for self or family member/friend)

⁶ To report the age of survey respondents, records were distributed into four relatively equal quartiles.

⁷ Respondents were asked whether they were of Hispanic origin and then asked to select one or more racial categories. Therefore, the category Hispanic includes any race. The categories African American and white include only non-Hispanic persons. Other races include 2% Asian, 2% American Indian/Alaska Native, 2% multiracial, and 2% refused or did not ask.

- Reason contacted CIS (information on smoking or other forms of tobacco, clinical trials, or assistance in communicating with health professionals)
- Mode of contact (telephone or *LiveHelp*)

For analyses purposes, the following two independent variables were recoded for simplifying the analyses: reason for contact and cancer site/type. Three key reasons for contact were of particular interest for this analysis: information about tobacco, inquiries about clinical trials, and help communicating with a health professional. Therefore, if respondents offered multiple reasons for their contact, they were sorted hierarchically for this analysis in that order. For example, if a respondent contacted CIS for information about tobacco and help in communicating with a health professional, they were coded as a tobacco contact in the analysis. If a user contacted CIS about more than one cancer site/type, only the first site/type coded in the ECRF was used. Therefore, this analysis does not examine users contacting CIS about multiple sites/types of cancer but instead looks only at the first site/type that was recorded by the Information Specialist.

This survey was designed, conducted, and analyzed such that the data can be generalized to the universe of CIS users. In some cases, however, differences in proportions between groups of survey respondents on a given question do not reflect statistically significant differences in the user population as a whole. This may be due to large standard errors resulting from small sample size or no differences being found between groups. As for all generalized survey data, readers should be aware that descriptive statistics about the universe of users in this report are associated with a standard error and a resulting confidence interval around each statistic. All specific statements of comparison made in this report have been tested for statistical significance through *t*-tests and are all significant at the 95 percent confidence level or better. It is important to note that only selected findings are presented for each topic in this report. Throughout this report, differences may appear large in some cases, but may not be statistically significant due to large standard errors. In other cases, there may be statistical significance, but substantively the comparison is not of interest. Standard errors for responses in this survey can be found in Appendix G.

2.10 Limitations

This study has some limitations. First, this was a survey of all first-time CIS users. This population may differ from users who access the service multiple times, but these differences are not known. Second, this survey was designed initially to compare telephone users with those who used the

LiveHelp online service. However, too few *LiveHelp* respondents were recruited in the study to make meaningful comparisons between the two groups. Another recruiting process might increase participation of *LiveHelp* users. Third, sample sizes were too small to produce many important results for some subsets of users such as smokers seeking help to quit or cutback or persons contacting CIS about clinical trials who did not plan to follow-up to find out if they were eligible for a trial. Finally, many of the user characteristics used for analysis may correlate with each other. For example, level of education and race are often correlated with one another. However, this analysis treats them separately.

3. FINDINGS

3.1 Demographic Information

A wealth of information was gathered about the persons who contacted CIS for cancer or tobacco information. Two sources were used to obtain information for analysis: the Electronic Contact Record Form (ECRF) collected by CIS and the 2003 User Survey designed by Westat in collaboration with NCI Project Officers. Table 4 shows the characteristics of CIS users, including the means they used to contact CIS (telephone or online); the person who was the subject of the contact; the reason for the CIS contact; the site/type of cancer, if applicable; and selected demographic information.

The vast majority of users (97%) contacted CIS using the 1-800-4-CANCER or 1-877-44U-QUIT telephone numbers, 8% used the *LiveHelp* online instant messaging service, and 5% used both modes of contact. People contacted CIS for themselves or for friends or family members. While the persons about whom the contacts were made typically had been diagnosed with cancer, their cancer types or sites varied widely. Just over half of users contacted CIS for themselves (57%), and the remaining users contacted the Service for a family member or friend (43%). Sixty-two percent of users indicated they or the person they contacted CIS about had been diagnosed with cancer. The cancer site/type relevant to the inquiry varied among CIS users: 21% of contacts were related to breast cancer, followed by those about lung (13%), prostate (7%), and colorectal (7%) cancer. Twelve percent of contacts were about a site/type of cancer other than those listed above, and 40% were not about a specific site/type of cancer because the reason for contact was about benign conditions, general cancer questions, or cancer-related questions that did not relate to a specific cancer site or type.

Survey results show that persons contacting CIS for information did so for a wide variety of topics, and many contacted about multiple reasons. However, three key reasons were of particular interest for this analysis: information about tobacco, inquiries about clinical trials, and help communicating with a health professional. Therefore, if respondents offered multiple reasons for their contact, they were sorted hierarchically for this analysis in that order. Of the three key reasons for contacting CIS, the most common was to obtain information about clinical trials (44%). In addition, about one-quarter of users (23%) contacted CIS to get help communicating with their doctor or other health professional. Just 8% of users contacted CIS to get information about tobacco, and the majority of those users wanted information about ways to quit or cut back on smoking (89%). One-quarter of users (24%) mentioned other reasons for contacting CIS.

Table 4.—Characteristics of CIS users: 2004

User characteristic	All CIS users		CIS users contacting for self		CIS users contacting for family member or friend	
	Number	Percent	Number	Percent	Number	Percent
Total.....	24,540	100	13,930	100	10,480	100
User type						
Contacted for self.....	13,930	57	—	—	—	—
Contacted for family member or friend.....	10,480	43	—	—	—	—
Diagnosed with cancer.....	14,980	62	6,390	47	8,590	84
Not diagnosed with cancer.....	9,000	38	7,320	53	1,670	16
Reason contacted CIS						
Information about tobacco.....	1,990	8	1,620	12	340	3
Ways to quit or cut back smoking.....	1,770	7	1,490	76	250	13
Ways to quit or cut back other tobacco.....	150	1	‡	‡	‡	‡
Other information about tobacco.....	260	1	‡	‡	‡	‡
Information about clinical trials ¹	10,820	44	5,530	40	5,270	51
Help communicating with health professional.....	5,680	23	3,230	23	2,430	23
Other reasons for contact.....	5,937	24	3,510	25	2,360	23
Cancer site/type						
Breast.....	5,090	21	3,700	27	1,370	13
Lung.....	3,280	13	1,940	14	1,320	13
Prostate.....	1,790	7	1,170	8	620	6
Colorectal.....	1,620	7	660	5	950	9
Other cancer site(s).....	3,010	12	4,510	32	5,220	50
Not applicable/no cancer site/type specified.....	9,760	40	1,960	14	990	9
Level of education						
High school or less.....	8,090	33	5,000	36	3,070	29
Some college.....	7,360	30	4,310	31	3,610	29
College graduate or higher.....	9,020	37	4,580	33	4,360	42
Sex						
Female.....	18,320	75	9,900	71	8,340	80
Male.....	6,220	25	4,020	29	2,140	20
Age²						
40 and under.....	6,680	27	3,300	24	3,320	32
41–50.....	5,450	22	2,730	20	2,690	26
51–60.....	5,410	22	3,340	24	2,040	19
61 or older.....	6,980	28	4,550	33	2,420	23
Race/ethnicity³						
White, non-Hispanic.....	18,510	75	10,550	76	7,850	75
African American, non-Hispanic.....	2,720	11	1,640	12	1,070	10
Hispanic.....	1,440	6	730	5	710	7
All other races.....	1,870	8	1,010	7	860	8
Mode of contact⁴						
Telephone.....	23,730	97	13,600	98	10,020	96
LiveHelp.....	2,060	8	330	2	460	4

— Not applicable.

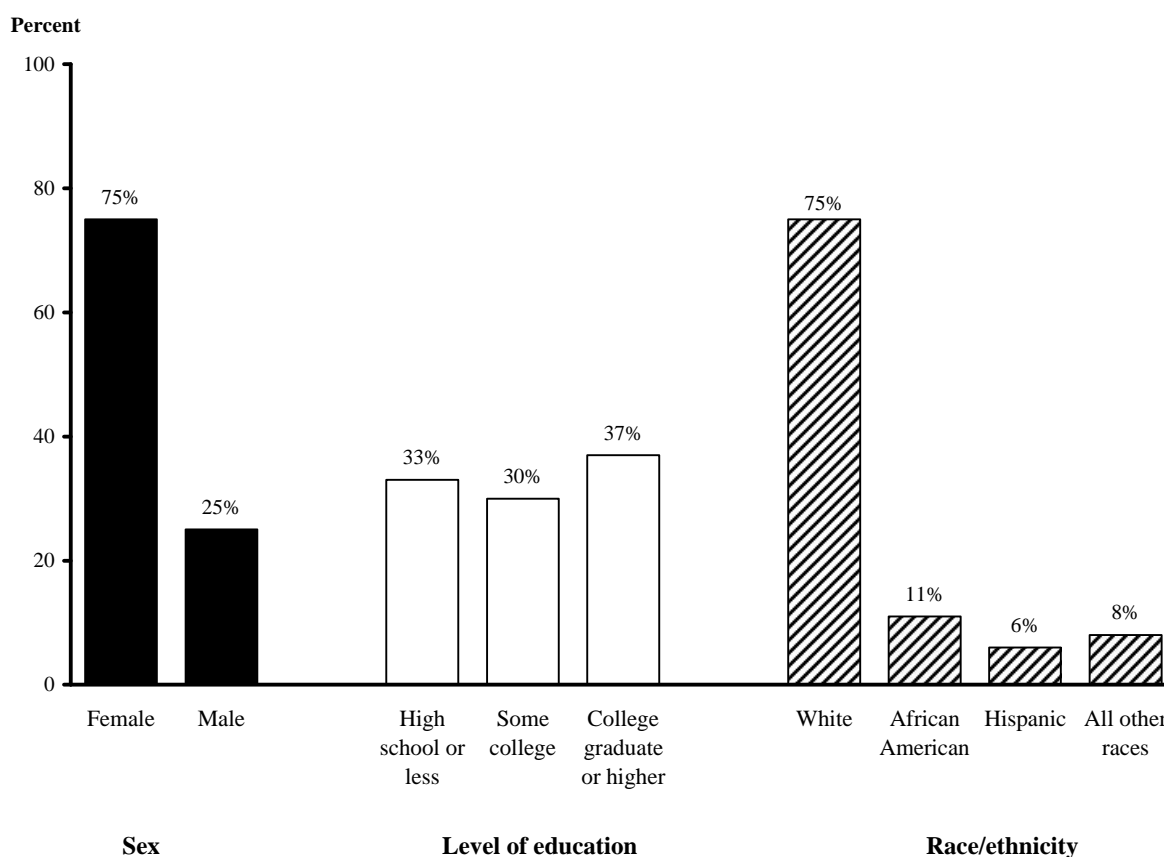
‡Reporting standards not met; less than 30 unweighted cases in cell.

¹Includes those users who specifically requested clinical trials information and does not include those who received information on clinical trials at the discretion of the CIS Information Specialist.²To report the age of survey respondents, records were distributed into four relatively equal quartiles.³Respondents were asked whether they were of Hispanic origin and then asked to select one or more racial categories. Therefore, the category Hispanic includes any race. The categories African American and white include only non-Hispanic persons. Other races include 2% Asian, 2% American Indian/Alaska Native, 2% multiracial, and 2% refused or did not ask.⁴Percents will not sum to 100 because respondents could select more than one mode of contacting CIS. Five percent indicated that they used both modes.

NOTE: Some data for this table were obtained through CIS Electronic Contact Record Form (ECRF) records. Numbers and percents may not sum to totals due to rounding and/or missing values.

More than one-third of CIS users had a college degree or higher (37%), followed by those with some college education (30%), or a high school education or less (33%). The majority were female (75%). Just over one-quarter (27%) were age 40 and under, 22% were between the ages of 41 and 50, 22% were between the ages of 51 and 60, and 28% were age 61 or over. Three-quarters of CIS users were white, 11% were African American, 8% were from other racial groups, and 6% were of Hispanic origin. For analysis and reporting purposes, persons of all races who identified themselves as Hispanic or Latino were placed in that category only, thus permitting Hispanics or Latinos to be identified as a single group.

Figure 1.—Demographic distribution of CIS users sex, level of education, and race/ethnicity: 2004



NOTE: Standard errors for the reported percents are female 0.2, male 0.2; high school or less 0.1, some college 0.1, college graduate or higher 0.0; and white 0.3, African American 0.1, Hispanic 0.1, and all other races 0.3.

Some variation was found in user characteristics between persons who contacted CIS for themselves and those who contacted CIS for a family member or friend. Nearly half of users contacting for themselves had been diagnosed with cancer (47%). In contrast, 84% of those who contacted CIS for a family member or friend said that the person they were contacting CIS about had been diagnosed with cancer. Twelve percent of users contacting CIS for themselves wanted information about tobacco compared with 3% of those contacting for a family member or friend. Forty percent contacted CIS for

themselves to seek information about clinical trials, and about one-quarter wanted help communicating with health professionals. Among users who contacted CIS for a friend or family member, half were seeking information about clinical trials, and one-quarter (23%) asked for help communicating with health professionals.

The demographic distribution was similar among all users. However, users who contacted CIS for a family member or friend tended to be more educated and female: 42% had a college degree or higher and 80% were female. In contrast, 33% of users who contacted for themselves had a college degree or higher and 71% were female. Users who contacted for themselves were more likely to be older (33% were age 61 or older), while those who contacted CIS for a family member or friend tended to be younger (32% were age 40 or under).

Data were examined to measure whether variation existed among the characteristics of those who contacted CIS for the three key reasons of contact (information about tobacco, clinical trials, or for help communicating with health professionals). Overall, the characteristics of users seeking information about clinical trials and help communicating with health professionals were similar, while those who contacted CIS about tobacco information had somewhat different characteristics (Table 5).

Users who contacted CIS about tobacco information were more likely to contact CIS for themselves and were less likely to be diagnosed with cancer. Specifically, 82% of users seeking information about tobacco contacted CIS for themselves, compared to 51% who were seeking clinical trials information and 57% who wanted help communicating with a health professional. In addition, only 20% of those asking for tobacco information were diagnosed with cancer (or had a friend or family member who was diagnosed). In contrast, over half of users seeking clinical trial information (51%) or help communicating with a health professional (57%) had been diagnosed.

Some demographic variation also was found among users who contacted CIS for tobacco information compared to those who contacted for other reasons. Only 17% of people seeking tobacco information had a college degree or higher, compared to 42% of those seeking clinical trials information and 40% of users who wanted help communicating with health professionals. Users seeking tobacco information were also less likely to be female (68% compared to 73% of users seeking clinical trial information and 76% of users seeking help communicating with health professionals).

Users seeking tobacco information were younger than other users: 37% were age 40 and under and 16% were age 61 or older. Among users seeking clinical trials information, 26% were age 40 and under and 28% were age 61 or older. The age distribution was similar for users seeking clinical trial information and those who wanted help communicating with a health professional. Thirty percent of

users who wanted help communicating with a health professional were age 40 and under and 30% were age 61 or older.

Table 5.—All CIS users by reason for contact, by selected characteristics: 2004

User characteristic	Reason for contacting CIS					
	Information about tobacco ¹		Clinical trials information		Help communicating with health professionals	
	Number	Percent	Number	Percent	Number	Percent
Total.....	1,990	100	10,820	100	5,680	100
User type						
Contacted for self.....	1,590	82	5,430	51	3,160	57
Contacted for family member or friend.....	340	18	5,180	49	2,390	43
Diagnosed with cancer.....	380	20	7,135	67	3,923	71
Not diagnosed with cancer.....	1,540	80	3,480	33	1,624	29
Level of education						
High school or less.....	830	43	3,190	30	1,770	31
Some college.....	780	40	3,070	29	1,660	29
College graduate or higher.....	330	17	4,490	42	2,240	40
Sex						
Female.....	1,330	68	7,890	73	4,290	76
Male.....	620	32	2,910	27	1,370	24
Age						
40 and under.....	730	37	2,800	26	1,670	30
41–50.....	440	22	2,450	23	1,219	22
51–60.....	480	24	2,550	24	1,050	18
61 or older.....	310	16	2,990	28	1,720	30
Race/ethnicity						
White, non-Hispanic.....	1,330	68	8,130	75	4,310	76
African American, non-Hispanic.....	270	14	1,190	11	630	11
Hispanic.....	240	12	580	5	330	6
All other races.....	‡	‡	900	8	400	7

‡Reporting standards not met; less than 30 unweighted cases in cell.

¹Includes users who contacted CIS for ways to quit or cutback smoking or using other tobacco or for other information about tobacco.

NOTE: Percents may not sum to 100 due to rounding.

In addition, racial differences were found among users who contacted for tobacco information compared to those who contacted for other reasons. Two-thirds (68%) of users who contacted CIS for tobacco information were white, compared to 75% of those who contacted for clinical trials information and 76% who wanted help communicating with a health professional.

In order to examine possible demographic changes in CIS users over time, three key variables from this study, sex, age, and race, were compared with the findings from the 1996 User Survey (Table 6). A crude comparison shows that the demographic composition of CIS users may be changing slightly. For example, the 1996 study reported that users were 80% female and 20% male, and the 2003 study found that 75% were female and 25% were male. This may indicate that males are increasing their use of the Service, however standard errors from the 1996 survey were not available to confirm statistical

differences between the 1996 and 2003 study. Although differences are negligible with regard to age, it may be possible to conjecture some change in the racial/ethnic distribution of users over time by comparing the two studies. In 1996, 90% of the users were white, 6% were African American, 3% were Hispanic⁸, and 2% were of some other race. Findings indicate that in 2004, 75% of the users were white, 11% were African American, 8% were of some other race, and 6% were of Hispanic origin, which may indicate that users are becoming more diverse with regard to their racial/ethnic background.

Table 6.—Comparison of selected CIS user characteristics: 1996 and 2004

User characteristic	1996	2004
Total	100%	100%
Sex		
Female.....	80	75
Male	20	25
Age		
40 and under.....	25	24
41–50	24	22
51–60	20	22
61 or older.....	31	31
Race/ethnicity		
White, non-Hispanic	90	75
African American, non-Hispanic	6	11
Hispanic	3	6
All other races	2	8

NOTE: Percents may not sum to 100 due to rounding.

3.2 CIS Users' Knowledge About Their Reason for Contact

3.2.1 Users' Perceived Knowledge Prior To and After CIS Contact

A key expectation for users of the information service is that they will become more knowledgeable about their subject of inquiry as a result of their contact. This outcome was measured in several ways. First, users were asked to rate themselves with regard to prior knowledge about the reason they contacted CIS. Then they were asked a follow-up question about the extent to which they felt their knowledge about cancer or a tobacco-related issue had increased as a result of their contact with CIS. Two other measures were used to assess knowledge. Users were asked to what extent the information they received was new to them. Also, users who did not specifically ask for the clinical trials information they received from the CIS Information Specialist were asked if they had been aware of clinical trials prior to their CIS contact.

⁸ Reflective of the 2000 change in how racial and ethnic demographic information is gathered, the 1996 User Survey data reports Hispanics as a racial category while in the 2003 User Survey, respondents were first asked if they were Hispanic or Latino and then asked to provide their race.

Findings indicate that, overall, CIS users perceived themselves as having variable levels of knowledge (Table 7). Nearly half (46%) of all users reported they felt only somewhat knowledgeable about cancer or a tobacco-related issue prior to contacting CIS. Thirteen percent perceived themselves as very knowledgeable, 27% felt knowledgeable, and 14% felt not at all knowledgeable.

Table 7.—Percent of all CIS users reporting various levels of knowledge prior to contact and the perceived effect of CIS contact on knowledge, by selected characteristics: 2004

User characteristic	Knowledge prior to contacting CIS				Knowledge increase after contacting CIS			
	Very knowledgeable	Knowledgeable	Somewhat knowledgeable	Not at all knowledgeable	A lot	Somewhat	A little	Not at all
Total	13	27	46	14	39	34	13	14
Diagnosis								
Diagnosed with cancer	13	27	46	15	43	36	11	10
Not diagnosed with cancer	12	28	47	13	33	31	15	21
Cancer site/type								
Breast	13	29	44	15	36	36	11	17
Lung	12	32	41	15	31	33	14	22
Prostate	‡	27	49	‡	40	33	17	‡
Colorectal	‡	27	49	‡	38	41	‡	‡
Other cancer site(s)	19	29	41	11	37	28	15	21
Not applicable/no cancer site specified	11	24	49	16	45	34	12	9
Level of education								
High school or less	11	23	46	19	40	31	15	14
Some college	11	26	48	15	43	33	11	13
College graduate or higher	15	31	44	10	36	37	12	15
Sex								
Female	13	28	45	14	40	35	11	14
Male	12	25	48	15	37	31	17	15
Age								
40 and under	10	27	47	15	44	34	12	10
41–50	11	25	49	15	38	35	13	14
51–60	14	29	41	16	37	35	12	16
61 or older	15	28	46	12	37	32	14	17
Race/ethnicity								
White, non-Hispanic	13	29	45	13	37	35	13	15
African American, non-Hispanic	12	22	50	17	43	33	10	15
Hispanic	‡	21	47	‡	54	28	‡	‡
All other races	‡	20	48	20	42	29	18	‡

‡Reporting standards not met; less than 30 unweighted cases in cell.

NOTE: Percents may not sum to 100 due to rounding and missing cases.

Differences in level of education were associated with perceived knowledge prior to CIS contact. College graduates were more likely than those with lower education to report that they were very knowledgeable (15% vs. 11% for at least some high school and some college) or knowledgeable (31% vs. 23% and 26%, respectively) prior to their contact with CIS. Similarly, users with at least some high

school education (19%) were more likely than either college graduates (10%) or those with some college (15%) to report they were not at all knowledgeable about their subject of inquiry prior to contacting CIS.

Differences were also found by other demographic variables. For example, whites (29%) were more likely than African Americans (22%), all other races (20%), and those of Hispanic origin (21%) to report being knowledgeable about their cancer or tobacco topic. Users age 40 or younger (10%) were less likely than users 61 and older (15%) to describe themselves as very knowledgeable about cancer or a tobacco-related issue prior to their CIS contact.

Respondents were also asked to report on changes in their knowledge about cancer and/or the harmful effects of tobacco following their CIS contact. Users most frequently reported that their knowledge had increased a lot (39%) or somewhat (34%). Interestingly, users who had a personal relationship to cancer (self, family member or friend diagnosed with cancer) were more likely to report that their knowledge had increased a lot (43%) or somewhat (36%) when compared to those who did not have a personal relationship with cancer (33% and 31%, respectively). Further, those who did not have a personal relationship with cancer more often reported that their knowledge increased a little (15%) or not at all (21%) when compared to those who did (11% and 10%, respectively). Users with some college were more likely than college graduates to report their knowledge had increased a lot after their contact with CIS (43% vs. 36%), and, although not a significant difference, 40% of those with a high school education or less reported that their knowledge increased a lot. Interestingly, Hispanic users reported a more beneficial outcome from their CIS contact than did people of other races/ethnicities. Fifty-four percent of Hispanics reported their knowledge had increased a lot after their contact with CIS, while only 42% of users from all other races, 43% of African Americans, and 37% of whites agreed with this statement. Younger people (age 40 or younger) were more likely to report that their knowledge had increased a lot after their contact than older users (44% vs. 38% for 41–50, 37% for 51–60, and 37% for age 61 or over) and less likely to report that their knowledge had not increased at all (10%) when compared with users age 51–60 (16%) and 61 and older (17%).

Another way to measure the impact that CIS had on users' knowledge was to consider how users' perceived knowledge prior to contacting CIS was related to users' reported changes in knowledge after their contact, as shown in Table 8. The findings indicate that users with low levels of cancer and/or tobacco-related knowledge prior to contacting CIS were more likely to report high levels of increased knowledge following their CIS contact. For example, users who reported being not at all knowledgeable prior to CIS contact were more likely than others to indicate that CIS increased their knowledge a lot (52% vs. 31% very knowledgeable, 31% knowledgeable, and 43% somewhat knowledgeable). This indicates CIS success in imparting what could be very complicated information to those who have little frame of reference for it.

Table 8.—Increase in perceived knowledge following CIS contact, by level of reported prior knowledge: 2004

Knowledge prior to contacting CIS	Increased knowledge after contacting CIS			
	A lot	Somewhat	A little	Not at all
Very knowledgeable	31%	32%	13%	24%
Knowledgeable	31	40	11	18
Somewhat knowledgeable	43	34	13	10
Not at all knowledgeable.....	52	24	15	9

In gauging changes in knowledge, CIS was also interested in determining to what extent users perceived the information they received as new. Overall, regardless of their reason for contact, 41% of users indicated that all or most of the information they received was new to them, 38% agreed that some information was new, 12% said only a little of the information was new to them, and 9% reported that none of the information was new (data not shown in tables).

3.2.2 Users' Perceived Change in Knowledge About Tobacco

Users who contacted CIS for themselves about trying to quit or cut back on using tobacco were asked if the information they received from CIS changed the way they think about smoking or using other forms of tobacco. Nearly three-quarters (71%) of the persons who contacted CIS about their own tobacco use said that their contact with CIS changed their thinking (Table 9). While differences between tobacco users either did not exist or comparisons were unable to be made due to insufficient cases, one interesting finding emerged with regard to race/ethnicity. African Americans and Hispanics were more likely than whites to report they thought differently about reducing or eliminating their use of tobacco products after contacting CIS (87% and 87% vs. 65%).

Table 9.—Percent of CIS tobacco contacts for self (n=1,620) who reported a change in thinking about tobacco following CIS contact, by selected characteristics: 2004

User characteristic	Percent indicating CIS changed thinking
Total	71
Level of education	
High school or less	73
Some college	71
College graduate or higher	‡
Sex	
Female.....	74
Male	64
Age	
40 and under.....	76
41–50	79
51–60	62
61 or older.....	‡
Race/ethnicity	
White, non-Hispanic	65
African American, non-Hispanic	87
Hispanic	87
All other races	‡

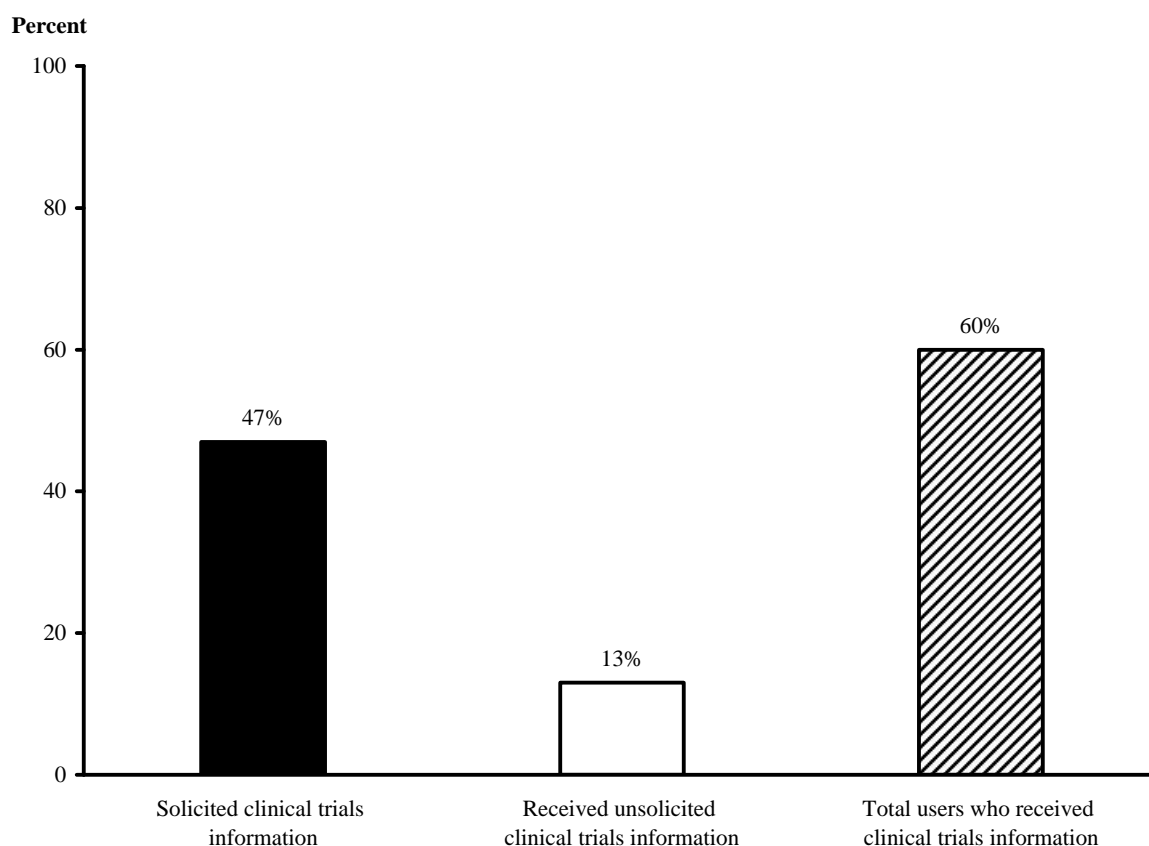
‡Reporting standards not met; less than 30 unweighted cases in cell.

NOTE: Percents may not sum to 100 due to rounding and missing cases.

3.2.3 Knowledge About Clinical Trials

Cancer research and treatment is greatly advanced through clinical trials, which require qualified and willing participants. By providing information about NCI’s research program and services, CIS actively promotes clinical trials. CIS disseminates clinical trials information in two important ways. Persons who contact CIS and specifically request information on clinical trials are provided with their desired information. In other cases, if a person contacts CIS about a subject related to clinical trials but has not specifically requested this type of information, and the CIS Information Specialist believes the user would benefit from receiving it, it is included in their discussion. In total, clinical trials information was disseminated to 60% of persons contacting CIS for cancer information; 47% of users requested the information, and 13% received clinical trials information at the discretion of the Information Specialist (Figure 2). The active role CIS takes in disseminating clinical trials information is important because 53% of the 13% of users who did not request clinical trials information but did receive it, said that they were unaware of clinical trials prior to their CIS contact (data not shown in table).

Figure 2.—Percent of all CIS users who received clinical trials information



NOTE: Standard errors for the reported percents are solicited clinical trials information 1.0; received unsolicited clinical trials information 0.8, and total users who received clinical trials information 1.0.

3.3 CIS Users' Self-Efficacy

One important objective of CIS is to increase users' self-efficacy with regard to communicating with health professionals about cancer and cancer-related topics. The degree to which this objective was met was measured by examining self-reports of changes in level of confidence following CIS contact for three key measures of communication. First, all persons in the study were asked to report on changes in their level of confidence regarding their ability to seek information about a cancer-related topic and/or a tobacco issue, if applicable. Two additional questions were asked only of specific groups. Users who contacted CIS for themselves and had previously indicated in the survey that they had not been diagnosed with cancer were asked about changes in their level of confidence with regard to understanding causes and/or risk factors for cancer. Those whose contact was for themselves and who had been diagnosed with cancer were asked about changes in their level of confidence with regard to actively participating in treatment decisions.

The findings from the study indicate that the CIS contact was responsible for increased confidence with regard to two of the three self-efficacy measures. Sixty-seven percent of all CIS users reported that they felt more confident in their ability to seek information following their contact with CIS (Table 10). In addition, 60% of those diagnosed with cancer and contacting for themselves reported feeling more confident in their ability to actively participate in their treatment decisions, compared with 39% of that type of user who reported no change in their level of confidence. Forty-five percent of CIS users who were not diagnosed with cancer reported feeling more confident in their ability to understand the causes and risk factors for cancer. However, a small majority (54%) reported no more confidence in ability following their CIS contact. Additional analyses were performed to examine whether this difference was due in part to higher levels of cancer and tobacco-related knowledge prior to contacting CIS or a smaller increase in knowledge from the contact. These analyses did not shed light on reasons for the difference. Because the cause of cancer is not known and some contacts with CIS did not touch on reasons or risk factors for cancer, an increase in confidence would not necessarily be expected.

Differences by user characteristics were found with regard to self-reports of changes in level of confidence for each of the three self-efficacy measures. For example, those who were diagnosed with cancer were more likely to report feeling more confident in their ability to seek information than those who were not diagnosed with cancer (72% vs. 59%), and those with some college were more likely than those with other levels of education to report this increased confidence (71% vs. 65% with high school or less and 65% with a college degree or more). In addition, women were more likely to report feeling more confident in their ability to seek information than were men (69% vs. 63%). Of note, 77% of Hispanic users reported feeling more confident in their ability to seek information following their CIS contact, as compared to whites (67%), African Americans, (64%), and users of all other races (64%). CIS users with a high school education or less were more likely than those with some college education to report no change in level of confidence in their ability to seek information (34% vs. 28%), and African American users were more likely than Hispanic users to report no change in confidence (35% vs. 22%).

The level of confidence of those not diagnosed with cancer in understanding the causes and risk factors for cancer also varied by selected characteristics. College graduates were the most likely to report no change in level of confidence following their CIS contact (61% vs. 51% of those with some college and 52% with high school or less). Fifty-two percent of CIS users age 40 or younger reported feeling more confident with regard to understanding causes and risk factors of cancer compared with 32% of users age 61 or older. Hispanics were more likely than whites to report feeling more confident in their ability to understand the causes and risk factors for cancer following their CIS contact (54% vs. 43%).

Table 10.—Effect of CIS contact on users' level of confidence, by selected characteristics: 2004

User characteristic	Confidence in ability to seek information ¹ (n= 24,540)			Confidence of those not diagnosed with cancer in understanding causes/risk factors for cancer ² (n=7,320)			Confidence of those with cancer in actively participating in treatment decisions ² (n=6,390)		
	More	Same	Less	More	Same	Less	More	Same	Less
Total percent	67%	31%	1%	45%	54%	‡	60%	39%	‡
Diagnosis									
Diagnosed with cancer.....	72	27	‡	—	—	—	60	39	‡
Not diagnosed with cancer.....	59	38	‡	45	54	‡	—	—	—
Cancer site/type									
Breast	67	31	‡	44	56	‡	64	36	‡
Lung.....	58	41	‡	36	63	‡	52	47	‡
Prostate.....	66	33	‡	‡	‡	#	62	38	#
Colorectal.....	68	31	1	44	‡	#	58	42	#
Other cancer site(s).....	61	37	‡	43	57	‡	67	33	#
Not applicable/no cancer site specified.....	72	27	‡	53	45	‡	‡	‡	‡
Level of education									
High school or less	65	34	‡	48	52	#	57	42	‡
Some college	71	28	‡	48	51	#	63	37	‡
College graduate or higher.....	66	32	‡	37	61	‡	62	37	‡
Sex									
Female.....	69	30	‡	46	53	‡	61	38	‡
Male	63	34	‡	42	57	‡	60	39	‡
Age									
40 and under.....	69	30	‡	52	47	‡	66	34	#
41–50	66	32	‡	48	52	#	56	44	‡
51–60	68	30	‡	44	54	‡	69	30	‡
61 or older	65	33	‡	32	67	‡	56	42	‡
Race/ethnicity									
White, non-Hispanic	67	31	‡	43	56	‡	60	39	‡
African American, non-Hispanic	64	35	‡	47	53	#	69	31	#
Hispanic	77	22	‡	54	‡	‡	‡	‡	#
All other races	64	33	‡	‡	‡	‡	‡	‡	‡

—Not applicable.

‡Reporting standards not met; less than 30 unweighted cases in cell.

Estimate is equal to 0 or rounds to 0.

¹Asked of all users.²Asked only of those contacting CIS for themselves.

NOTE: Percents may not sum to 100 due to rounding.

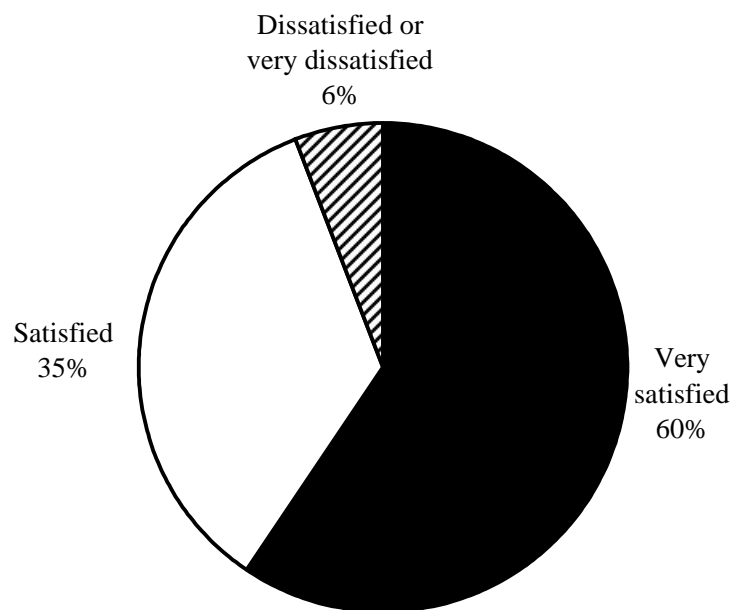
Among CIS users contacting for themselves who were diagnosed with cancer, little variation by demographic characteristics occurred with regard to changes in level of confidence in actively participating in treatment decisions. Only users between the ages of 51 to 60 were more likely than users between the ages of 41 to 50 and those age 61 or older to indicate more confidence in their ability to actively participate in their treatment decisions following their CIS contact (69% vs. 56% for each).

3.4 User Satisfaction With CIS Service

Measuring the satisfaction of CIS users was a critical component of the evaluation. To derive a full measure, respondents were asked about several items relating to different dimensions of satisfaction with the CIS. First, users were asked about their overall satisfaction with the Service. Next, users reported on whether their expectations for the contact were met, exceeded, or not met. Third, they were asked about their perception of the Information Specialist's knowledge; and finally, about their level of trust in the information they received from CIS.

Nearly all CIS users (95%) reported being satisfied (35%) or very satisfied (60%) with the service they received. Only 6% were dissatisfied or very dissatisfied (Figure 3 and Table 11). Those who had contacted CIS for a friend or family member were more likely than those who had contacted CIS for themselves to say they were very satisfied (64% vs. 56%). In addition, users who were diagnosed with cancer or had a friend or family member who was diagnosed were more likely to report being very satisfied than those contacting CIS about someone not diagnosed (62% vs. 57%). When looking at satisfaction by each of the key reasons users contacted CIS, users who wanted help communicating with a health professional were more likely than those seeking information about clinical trials to say they were very satisfied (66% vs. 59%).

Figure 3.—CIS users reporting overall level of satisfaction with CIS contact: 2004



NOTE: Standard errors for the reported percents are very satisfied 1.1, satisfied 1.1, dissatisfied or very dissatisfied 0.5.

Table 11.—Dimensions of satisfaction with CIS contact, by selected characteristics: 2004

User characteristic	Overall satisfaction			Expectations		
	Very satisfied	Satisfied	Dissatisfied or very dissatisfied	Exceeded	Met	Not met
Total.....	60%	35%	6%	30%	59%	12%
User type						
Contacted for self.....	56	37	7	26	62	13
Contacted for family member or friend.....	64	31	4	34	55	11
Diagnosis						
Diagnosed with cancer.....	62	33	6	32	56	12
Not diagnosed with cancer.....	57	38	6	25	63	12
Reason contacted CIS						
Seeking information about tobacco.....	61	34	†	30	59	11
Seeking clinical trials information	59	35	6	31	59	10
Help communicating with a health professional.....	66	31	†	33	58	9
Other reasons for contact	54	37	9	23	60	17
Level of education						
High school or less	54	38	8	21	62	17
Some college	64	32	†	31	60	10
College graduate or higher.....	62	33	5	35	55	10
Sex						
Female	62	33	5	30	58	11
Male.....	53	39	8	26	60	14
Age						
40 and under	64	32	†	37	55	8
41–50	59	35	6	28	59	13
51–60	58	36	6	32	56	11
61 or older	57	35	8	21	64	16
Race/ethnicity						
White, non-Hispanic	62	33	6	30	58	12
African American, non-Hispanic	53	41	†	20	65	14
Hispanic	56	39	†	36	57	†
All other races	52	41	†	27	57	†

See notes on next page.

Table 11.—Dimensions of satisfaction with CIS contact, by selected characteristics: 2004—continued

User characteristic	Knowledge of information specialist ¹		Trust in information ²	
	Very knowledgeable	Knowledgeable or somewhat knowledgeable	A lot	Somewhat or a little
Total.....	52%	46%	83%	16%
User type				
Contacted for self.....	51	47	81	17
Contacted for family member or friend.....	54	45	84	15
Diagnosis				
Diagnosed with cancer.....	53	46	82	16
Not diagnosed with cancer.....	52	47	83	15
Reason contacted CIS				
Seeking information about tobacco.....	58	41	86	13
Seeking clinical trials information	53	45	82	17
Help communicating with a health professional	54	45	83	16
Other reasons for contact	49	49	83	15
Level of education				
High school or less	49	50	80	18
Some college	59	40	84	15
College graduate or higher.....	50	48	83	15
Sex				
Female	53	46	83	16
Male.....	51	47	81	16
Age				
40 and under	54	45	86	14
41–50.....	51	47	83	15
51–60.....	53	46	81	17
61 or older	51	46	81	17
Race/ethnicity				
White, non-Hispanic	53	46	84	15
African American, non-Hispanic	51	46	77	21
Hispanic	63	36	82	‡
All other races	45	54	77	‡

‡Reporting standards not met; less than 30 unweighted cases in cell.

¹Insufficient cases to report “not at all knowledgeable” category by user characteristics (less than 2%).

²Insufficient cases to report “not at all” category by user characteristics (less than 2%).

NOTE: Percents may not sum to 100 due to rounding.

Users who were very satisfied with CIS overall had higher education levels, were female, and were younger. For example, users with some college (64%) and with a college degree (62%) were more likely to report being very satisfied than were users with a high school education or less (54%). Women were more likely than men to say they were very satisfied with the Service (62% vs. 53%). Level of satisfaction was also related to age. Sixty-four percent of users age 40 and under reported being very satisfied compared with 58% of users age 51–60 and 57% of users age 61 or older. In addition, whites were more likely than African Americans and all other races to say they were very satisfied (62% vs. 53% and 52%, respectively).

3.4.1 CIS Users' Expectations for Their Contact

All CIS users were asked whether the expectations they held about contacting CIS were met, exceeded, or not met. On this measure, CIS also scored well. Fifty-nine percent said their expectations were met and another 30% said the Service exceeded their expectations (Table 11). Similar to the findings for overall satisfaction, this dimension of satisfaction varied by demographic group. Users who contacted for a family member or friend were more likely to say the Service exceeded their expectations (34% vs. 26%), which was also true for those who had a personal relationship with cancer compared to those who did not (32% vs. 25%). Among CIS users who said that their expectations were met, little variation was found based on whether they called for information on tobacco (30%), clinical trials (31%), and assistance in communicating with a health professional (33%). Those who contacted the Service seeking information not related to the three main topics of interest for CIS were the least likely (23%) to have their expectations exceeded.

On this dimension, users who said their expectations were exceeded were more likely to be educated, female, and younger. Specifically, the percentage of users who said their expectations were exceeded increased with education level, ranging from 21% of users with a high school education or less to 35% of those with a college degree or more. Women were more likely than men to say their expectations were exceeded (30% vs. 26%). CIS users age 40 and under were more likely to report that CIS exceeded their expectations when compared with those users age 61 and older (37% vs. 21%). Whites and Hispanics were more likely than African Americans to say their expectations for the contact with CIS were exceeded (30% and 36% vs. 20%).

3.4.2 Knowledge of Information Specialist

Another dimension of satisfaction is perception of the CIS Information Specialist's knowledge. Almost all users (98%) thought the Information Specialist was knowledgeable, including half (52%) who said the Specialist was very knowledgeable (Table 11). Opinions varied by demographic group. Users with some college education were more likely than those with both lower and higher education levels to say the Specialist was very knowledgeable (59% vs. 49% and 50%). In addition, Hispanic users were more likely than users of other racial/ethnic groups to think the Information Specialist was very knowledgeable (63% vs. 53% of whites and 51% of African Americans).

3.4.3 Trust in Information From CIS

CIS users had a high level of trust in the information they received from CIS, another important dimension of satisfaction. Specifically, 83% said they trusted the information a lot compared with 16% of users indicating they trusted it somewhat or a little (Table 11). More educated and younger users were more likely to say they trusted the information a lot. Eighty-three percent of CIS users with a college degree or higher said they trusted the information a lot, compared to 80% of users with a high school degree or less. Level of trust was also related to age, such that users age 40 and under were more likely to report that they trusted the information a lot (86%) than users age 51–60 (81%) and those 61 or older (81%).

3.4.4 Satisfaction and Mode of Contact

The dimensions of satisfaction discussed above were also examined by user mode of contact to ascertain whether those contacting CIS by *LiveHelp* or by telephone had different levels of satisfaction. As Table 12 shows, the level of satisfaction across all the dimensions measured was essentially the same for both groups of users. For example, 60% of users who contacted CIS by telephone and 64% of those who used *LiveHelp* were very satisfied. For both modes of contact, 38% said the Service exceeded their expectations, about half said the Information Specialist was very knowledgeable, and over 80% said they trusted the information a lot.

Table 12.—Dimensions of satisfaction, by mode of CIS contact: 2004

Dimension of satisfaction	Mode of contact	
	Telephone	<i>LiveHelp</i>
Total	100	100
Overall satisfaction		
Very satisfied	60	64
Satisfied	34	33
Dissatisfied or very dissatisfied.....	6	†
Expectations		
Exceeded.....	38	38
Met.....	56	55
Not met	†	†
Knowledge of information specialist		
Very knowledgeable	53	49
Knowledgeable or somewhat knowledgeable.....	46	49
Not at all knowledgeable.....	2	†
Trust in information		
A lot	82	86
Somewhat or a little	16	†
Not at all	2	†

†Reporting standards not met; less than 30 unweighted cases in cell.

NOTE: Percents may not sum to 100 due to rounding.

3.4.5 Satisfaction and Self-Efficacy

The three measures of self-efficacy were also examined by overall level of satisfaction with the CIS service. Increased self-efficacy was related to overall satisfaction with CIS. Among all CIS users, those who reported feeling more confident in their ability to seek more information were more likely than users who reported no change in their level of confidence on this issue to report that they were very satisfied with CIS overall, (71% vs. 37%) (Table 13).

The same pattern holds true with regard to confidence in understanding the causes and risk factors for cancer and confidence in one's ability to actively participate in treatment decisions. For example, among users contacting for themselves and not diagnosed with cancer, 65% of those who reported feeling more confident in their ability to understand the causes and risk factors for cancer also reported feeling very satisfied, compared with 47% who felt that their level of confidence had not changed following their CIS contact. Among users diagnosed with cancer, 72% of those indicating that they felt more confident in actively participating in treatment decisions reported being very satisfied with CIS, while just 38% of those reporting no change in confidence did so.

Table 13.—Level of satisfaction with CIS contact by effect on level of confidence: 2004

CIS affected users' confidence in:	Very satisfied	Satisfied	Dissatisfied or very dissatisfied
Total.....	60	35	5
Ability to seek information			
More	71	27	‡
Same.....	37	49	12
Understanding causes/risk factors for cancer¹			
More	65	34	‡
Same.....	47	42	10
Actively participating in treatment decisions²			
More	72	27	‡
Same.....	38	46	14

‡Reporting standards not met; less than 30 unweighted cases in cell.

¹This item was asked of all users who were contacting for themselves and not diagnosed with cancer.

²This item was only asked of users who were contacting for themselves and reported being diagnosed with cancer.

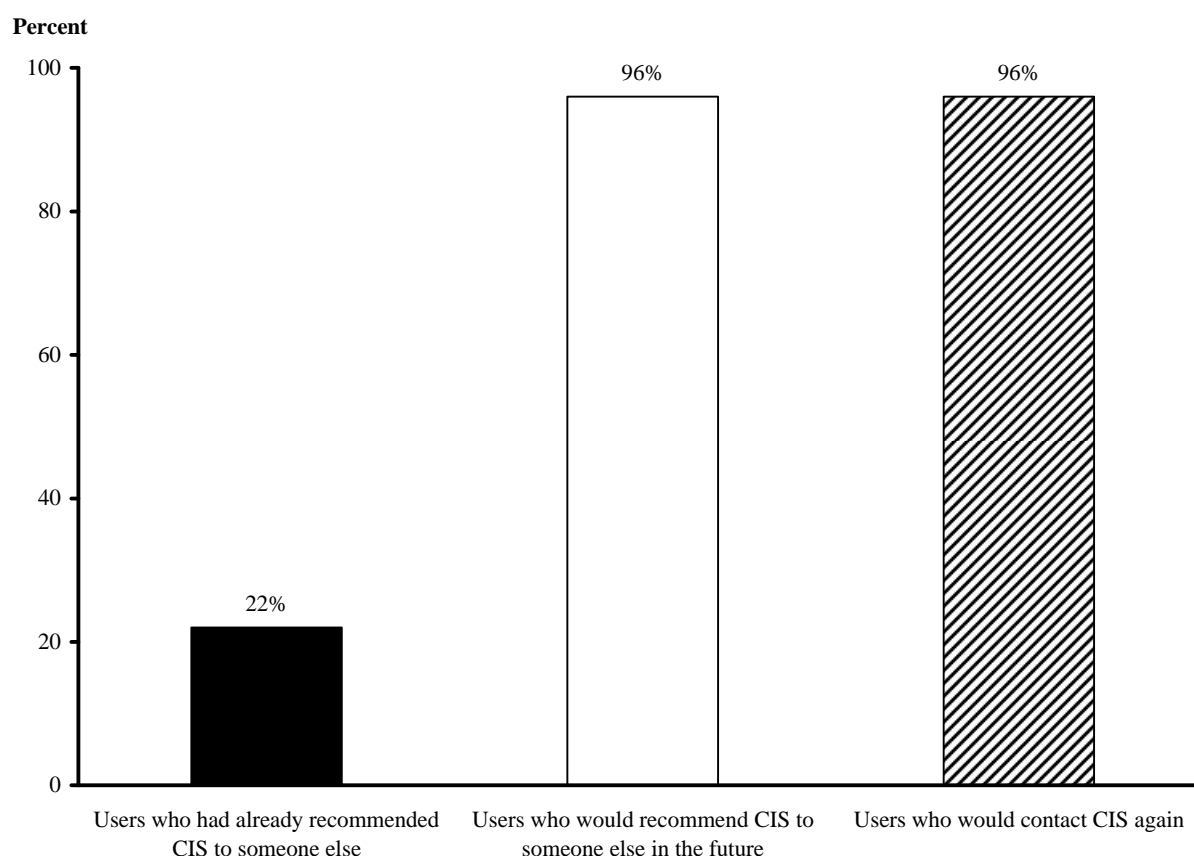
3.4.6 Satisfaction With CIS Materials or Web Referrals

Overall, users who received web links or were mailed material were very satisfied with the material they received. Among CIS users who used *LiveHelp*, three-quarters (76%) said they received links to web pages. Of those who received the links, over half (58%) were very satisfied with the links they received and another 32% were satisfied. Among CIS users who called by telephone, 71% said they were expecting to receive materials by mail from the Service, and the majority (94%) reported that they did receive the material. Similar to those who received web links, 59% were very satisfied with the mailed material and another 31% said they were satisfied. Only 2% said they were dissatisfied or very dissatisfied with the material they received. Users gave a variety of reasons for their dissatisfaction, including the perception that the material was not related to the reason they had called, they could not understand the material, or they never received it (data not shown in tables).

3.4.7 Recommending or Recontacting CIS

In addition to assessing dimensions of satisfaction, users were asked whether they would recommend the Service to others or contact the Service again themselves. Almost all (96%) of users said they would recommend CIS in the future and/or that they would recontact CIS (Figure 4). Twenty-two percent of users had already suggested someone they know contact CIS by the time of their interview.

Figure 4.—Percent of CIS users recommending CIS or saying they would contact CIS again: 2004



NOTE: Standard errors for the reported percents are users who had already recommended CIS to someone else 1.0, users who would recommend CIS to someone else in the future 0.4, users who would contact CIS again 0.4.

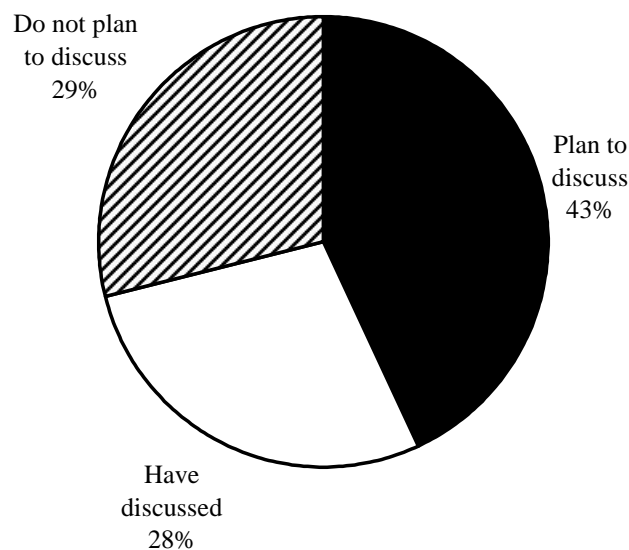
3.5 Intention and Behavior

Behavior change may be an important result of a contact with CIS, and the User Survey addressed it in several areas. This impact of CIS on their users was measured through self-reports of users' intention and behavior with regard to communication with a health professional, changes in tobacco use, and pursuit of clinical trials following their CIS contact. In order to increase the validity of these findings, the intention and behavior questions were only asked of those contacting CIS for themselves. First, users were asked to report on whether they intended to discuss or had discussed the information they received from CIS with their doctor or health professional following their contact with CIS. Smokers who contacted CIS for assistance in quitting or cutting back on their tobacco use were asked about any changes they had made following their contact with CIS. Finally, users who received information on clinical trials were asked about whether the information they received led them to seek more information about clinical trials and whether they had determined or planned to find out their eligibility to participate in clinical trials.

3.5.1 Users' Behavioral Intention and/or Behavior Related to Communicating With Health Professionals

Findings show that persons contacting CIS for themselves about either a cancer or tobacco issue regarded the information they received to be valuable in discussions with their doctors or other health professionals. In all, 71% indicated that the information they received from CIS had resulted in positive intention or behavior change. For instance, 28% of users said they had discussed the information they received from CIS with a health professional by the time of the survey, and another 43% said they planned to have such a discussion (Figure 5 and Table 14). Of the 28% of users who had already discussed the information with a health professional, 56% said the information helped them a lot, 31% reported somewhat, 8% said a little, and 5% said the information they received did not help them at all (data not shown in table).

Figure 5.—CIS users contacting for themselves reporting communication of information from CIS with a health professional (n=3,230): 2004



NOTE: Standard errors for the reported percents are: plan to discuss 1.5, have discussed 1.6, and do not plan to discuss 1.4.

Table 14.—CIS users who contacted for themselves reporting communication with a health professional (n=3,230), by selected characteristics: 2004

User characteristic	Have discussed	Plan to discuss	Do not plan to discuss
Total.....	28%	43%	29%
Diagnosis			
Diagnosed with cancer.....	37	42	21
Not diagnosed with cancer.....	20	43	36
Cancer site/type			
Breast	33	42	26
Lung.....	16	43	41
Prostate.....	29	51	‡
Colorectal.....	‡	‡	‡
Other cancer site(s).....	18	36	46
Not applicable/no cancer site specified.....	35	44	22
Level of education			
High school or less	26	46	28
Some college	27	43	30
College graduate or higher	32	39	29
Sex			
Female.....	29	42	29
Male	27	46	28
Age			
40 and under.....	30	43	27
41–50	32	42	27
51–60	29	43	28
61 or older.....	25	43	32
Race/ethnicity			
White, non-Hispanic	28	42	30
African American, non-Hispanic	25	49	27
Hispanic	40	40	‡
All other races	34	40	‡

‡Reporting standards not met; less than 30 unweighted cases in cell.

NOTE: Percents may not sum to 100 due to rounding and/or missing values.

Twenty-nine percent of users contacting for themselves said they did not plan to further discuss the information they received with a health professional. When asked, users gave a variety of reasons for not planning to talk with a doctor or health care professional (data not shown in table). Many simply said that they did not perceive a need to discuss the information they received. Some users reported they did not plan to discuss the information because they did not have cancer, did not have health insurance, or were not currently receiving medical treatment. A few said they were confirming information they already received from their doctor and further discussion was not warranted. Others said they needed to get more information before they would be willing to have a discussion with a health professional.

Discussion of information received from CIS with a health professional varied by some user characteristics. Those diagnosed with cancer were more likely than those not diagnosed to have already talked with their doctor or another health professional about the information they received from CIS (37% vs. 20%), and Hispanics (40%) were more likely than whites (28%) or African Americans (25%) to report having had a conversation with their doctor or health professional by the time of the interview.

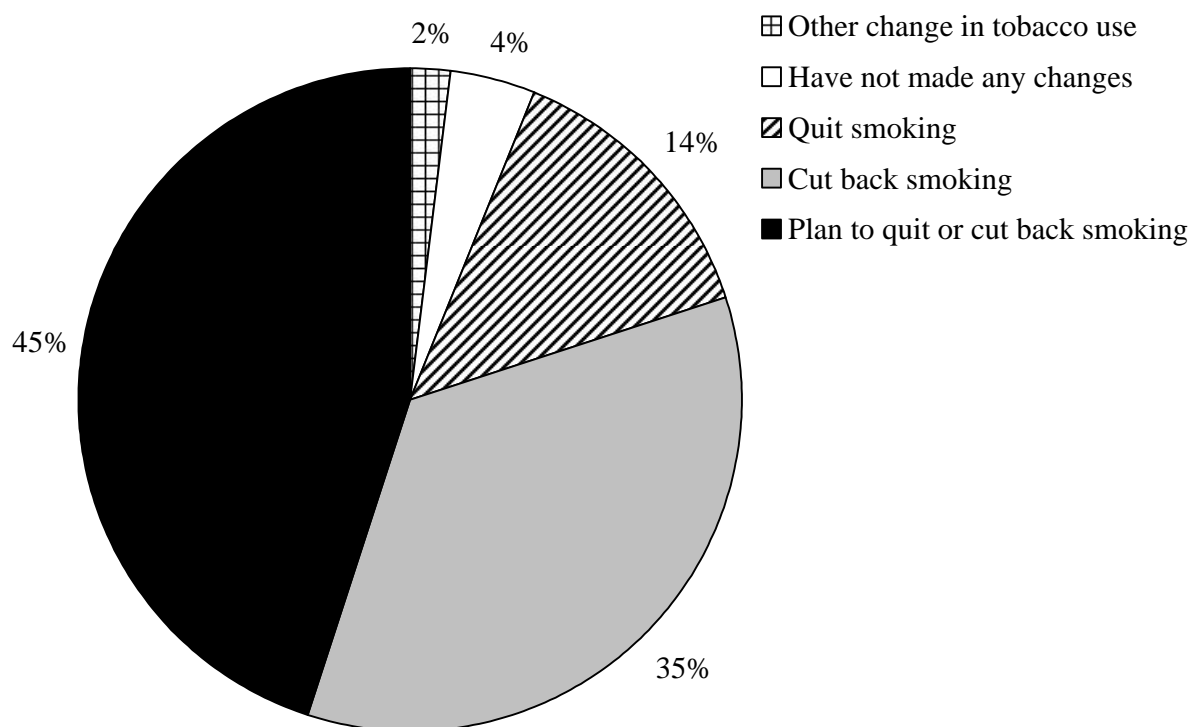
Some groups of users were less likely than others to report having discussed CIS information with a health professional or more likely to say they did not intend to further discuss this information. Persons age 61 or older were less likely than persons age 41–50 to have had a conversation with their doctor or health professional about the information they obtained from CIS (25% vs. 32%). Persons who contacted CIS about lung cancer were less likely than those contacting about an issue related to breast or prostate cancer to say that they had discussed the CIS information with a doctor or health professional (16% vs. 33% and 29%), and they were more likely than those contacting about breast cancer to say they did not plan to discuss the information they received with a doctor or health professional (41% vs. 26%). This is likely due to the promotion of the National Lung Cancer Screening Trial (NLST), which required that eligible participants not be diagnosed with cancer. Also, persons not diagnosed with cancer were more likely than those with cancer to say they did not plan to discuss the information they received (36% vs. 21%).

3.5.2 Smokers' Behavioral Intention and/or Behavior Change

CIS was particularly effective among users contacting CIS for themselves in influencing positive intentions and behavioral changes for ways to quit or cut back on smoking or using some other form of tobacco. When asked about specific changes they had made following their contact with CIS, 14% reported that they had quit smoking, 35% had cut back, and 45% indicated that they planned to quit or cut back in the future (Figure 6). Among smokers who reported already cutting back on their tobacco use, nearly all (96%) reported that they planned to quit. Of these, 40% indicated that they had set a quit date (Figure 7).

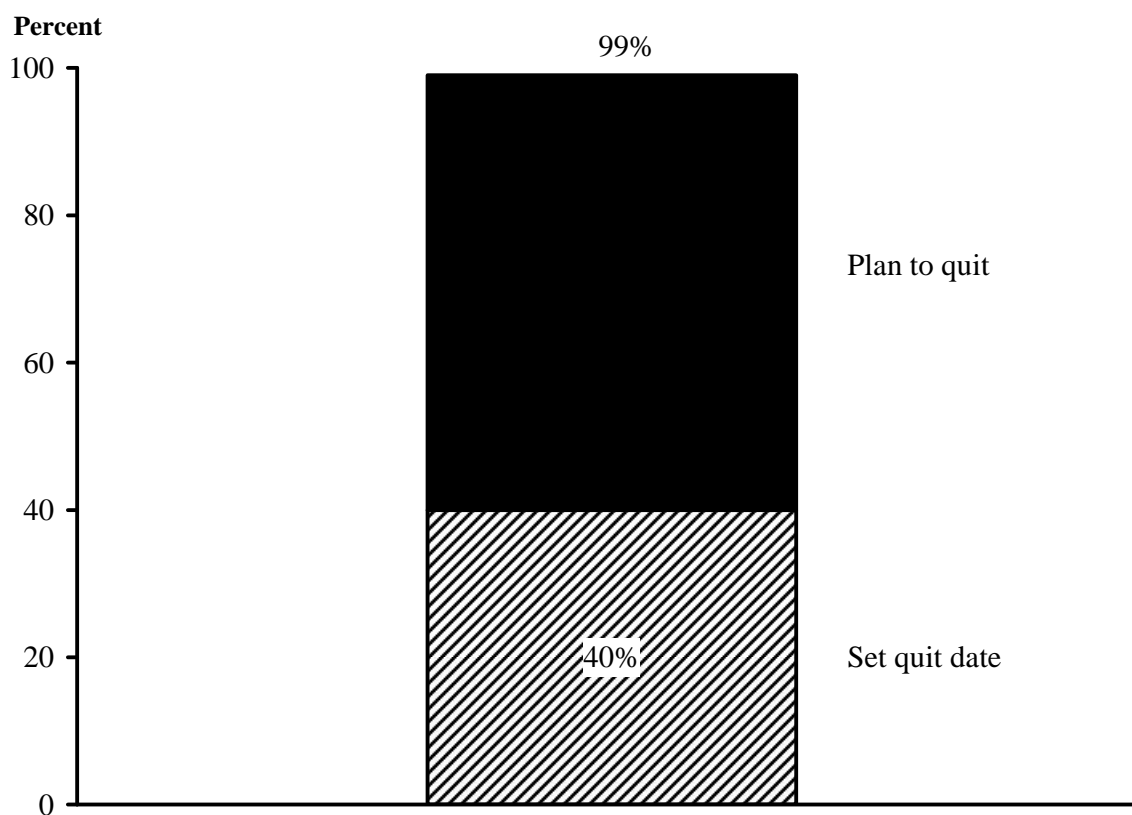
Smokers who reported making a change in their tobacco use since their contact with CIS were asked whether the suggestions from CIS helped them to quit, cut back, or plan to quit or cut back on smoking. Eighty-four percent reported that the suggestions from CIS did indeed help them to make a tobacco-related change in their lives (data not shown in tables).

Figure 6.—Effects of CIS contact on smoking-related behaviors and intentions: 2004



NOTE: Standard errors for the reported percents are: have not made any changes 1.4, quit smoking 2.4, cutback smoking 3.3, and plan to quit or cutback smoking 3.7.

Figure 7.—Effect of CIS contact on smoking-related intention: 2004



NOTE: Standard errors for the reported percents are: plant to quit smoking 1.8 and set quit date 3.0.

3.5.3 Users' Behavioral Intention and/or Behavior Related to Clinical Trials

The findings clearly indicate that CIS influenced both the intention and behaviors of users who either contacted CIS for clinical trials information or did not explicitly contact CIS for that type of information but received it through the course of the contact. Of those contacting for themselves and receiving clinical trials information, 39% reported that following their CIS contact, they had inquired about their eligibility to participate in clinical trials (Table 15). Of those who had not yet inquired about their eligibility, 83% indicated that they planned to do so. Interestingly, the findings varied by only one user characteristic; those not diagnosed with cancer were significantly more likely to report that they had inquired about their eligibility to participate in clinical trials following their CIS contact than were users who said they had been diagnosed with cancer (46% vs. 31%). Again, this is likely due to the promotion of NLST; 52% of those who were not diagnosed with cancer inquiring about their eligibility to participate in trials were contacting CIS for information about NLST.

Table 15.—Percent of CIS users contacting for themselves who received clinical trials information (n=5,530) reporting specific behavior or intention regarding eligibility for clinical trials, by selected characteristics: 2004

User characteristic	Inquired about eligibility to participate in clinical trials	Have not inquired but plan to find out if eligible
Total contacting for self receiving clinical trials information.....	39	83
Diagnosis		
Diagnosed with cancer.....	31	85
Not diagnosed with cancer.....	46	81
Level of education		
High school or less	41	87
Some college	36	80
College graduate or higher	37	81
Sex		
Female	37	83
Male.....	42	84
Age		
40 and under.....	‡	81
41–50	‡	87
51–60	50	79
61 or older	44	86
Race/ethnicity		
White, non-Hispanic	40	83
African American, non-Hispanic	‡	84
Hispanic	‡	‡
All other races	‡	‡

‡Reporting standards not met; less than 30 unweighted cases in cell.

The small percentage of users who stated that they had no intention of inquiring about their eligibility to participate in clinical trials were asked about their reasons (data not shown in tables). Most commonly, respondents could not articulate a reason and said simply they did not want to. Others said they needed to get more information first. A few respondents said they “did not want to be a guinea pig,” “didn’t know what to do,” or “where to look.”⁹

Among CIS users who inquired about their eligibility to participate in a clinical trial following their CIS contact, 4% reported that they were eligible to participate in a clinical trial, and almost half reported that they had actually enrolled in a clinical trial (data not shown in tables). The small percentage of users who were eligible but had not enrolled were asked their reasons for not enrolling in a trial.¹⁰ Again, reasons varied greatly; however, a common response was that they did not perceive a need or benefit to enrolling in a trial. Personal inconvenience was the second most common reason for not enrolling in a trial; some people said they were too busy, while others said they lived too

⁹ There were 34 unweighted cases in which users indicated no intention to inquire about their eligibility to participate in clinical trials.

¹⁰ There were 48 unweighted cases in which users indicated they were eligible to participate in a clinical trial but had not yet enrolled.

far away or did not have transportation. Others said they were not eligible to participate because they were too ill or too healthy.

All users who contacted CIS for themselves and received information about clinical trials were asked whether their CIS contact had led them to seek more information about clinical trials. Nearly half of users (49%) reported that this was the case (Table 16). Of these, persons age 40 and under were more likely than those ages 61 or older to seek additional information (57% vs. 45%). The remaining 51% who had not sought additional information about clinical trials were asked to report on their reasons for not seeking more information. While the responses varied greatly, the most commonly cited reasons were that they did not have enough information, had not read the information they received, or were unaware of how to follow up after their CIS contact. The next largest group of respondents said they were not interested in finding out more about clinical trials. Other frequently mentioned responses included “haven’t had a chance to talk with a doctor,” “not sure trial is available,” “not eligible to participate,” “personal inconvenience,” “comfortable with current treatment,” and “no perceived need.”

Table 16.—Percent of CIS users contacting for themselves and receiving information about clinical trials (n=8,040) who sought more information about clinical trials due to CIS contact: 2004

User characteristic	Percent
Total.....	49
Cancer site/type	
Breast	53
Lung	50
Prostate.....	52
Colorectal	42
Other cancer site(s).....	49
Not applicable/no cancer site specified.....	
Level of education	
High school or less	50
Some college	48
College graduate or higher	50
Sex	
Female	47
Male.....	54
Age	
40 and under.....	57
41–50	49
51–60	47
61 or older	45
Race/ethnicity	
White, non-Hispanic	49
African American, non-Hispanic	53
Hispanic	‡
All other races	‡

‡Reporting standards not met; less than 30 unweighted cases in cell.

3.6 Respondent's Summary Comments

At the conclusion of the survey, respondents were asked if they had any additional questions or comments. Nearly one-third of respondents (n=773) provided additional comments and oftentimes their main purpose for doing so was to express their appreciation for the assistance they received from CIS. Examples of the type of comments mentioned by respondents include the following:

CIS should continue doing what it's doing.

CIS has super people who go the extra mile. These people put a personal touch on the information. The user leaves the conversation confident that she has received the necessary information.

CIS is a wonderful service. It informs and encourages many people to take action who otherwise wouldn't know where to begin.

Glad I called because if I hadn't I probably would not have quit smoking. I have recommended the service to my husband.

They (CIS) were able to answer any question I had.

Respondents also identified areas in which they felt CIS excels. They mentioned a wide range of areas of success including courtesy, knowledge and professionalism, compassion and understanding, confidentiality, thoroughness, and responsiveness. Summarized comments that reflect these particular attributes include the following:

- Users are made a priority and are never rushed.
- CIS Information Specialists listen to the user and try to understand the situation, thereby ensuring all questions, even the questions the user didn't know how to ask, are addressed.
- CIS Information Specialists are able to empathize with users and offer hope.
- Users appreciate having someone to talk to without being concerned with personal consequences.
- Little or no waiting for materials.
- Users are confident that they have received and understand all pertinent information.
- Users remember the CIS number years after using it.

Some CIS users also identified growth opportunities or expressed areas where they did not feel their needs had been met fully. In some cases, users were disappointed by their perception that CIS lacked detailed treatment/trials information for their specific condition. Others expressed having a sense of "What's next?" and wished that CIS could provide follow-up services, especially in instances where

they felt overwhelmed by the amount of information and preferred to have it spread out over a number of contacts with CIS. Still other users felt CIS should be aware that not all users have access to a computer or that the information on the www.cancer.gov web site was considered by some to be better than information provided by telephone. Some respondents reported that being asked to participate in a survey during a stressful time was insensitive.

Some users also provided concrete suggestions for ways in which CIS could provide more resources, increase their visibility, and increase the interpersonal service provided. Their suggestions included the following:

- Provide a list of resources for uninsured/underinsured. Many treatments are not covered by insurance plans.
- Promote service more in doctors' offices and elsewhere to increase visibility of service.
- CIS employees should provide their name to increase personal connection.

4. CONCLUSIONS AND RECOMMENDATIONS

4.1 Characteristics of Users

Overall, some patterns emerged with regard to user characteristics for this study. In general, more than half of all CIS users contacted CIS for information about themselves and just under two-thirds of all users were either diagnosed with cancer themselves or contacting for a friend or family member who had been diagnosed. Of those calling for information for a friend or family member, many reported that this person had been diagnosed with cancer. Nearly all users contacted CIS by telephone using 1-800-4-CANCER or the Quit Line 1-877-44U-QUIT, although a small percentage contacted the Service via *LiveHelp*, CIS' online service. An even smaller group of users said that they contacted CIS using both modes. The most common reason for contacting the CIS was to obtain information about clinical trials and the most common cancer site/type mentioned was breast cancer. Users also contacted the CIS for information about tobacco and for help communicating with a health professional.

CIS users were typically white, female, and had either attended some college or had a college degree or higher level of education. Three-quarters of those contacting CIS were female and the same proportion said they were white. African Americans were the second largest racial/ethnic group followed by Hispanics and all other races. Two-thirds of users had either some college, were a college graduate, or had a higher level of education and the remaining third had a high school education or less than a high school education.

4.2 Satisfaction With CIS

Overwhelmingly, persons who contacted CIS by telephone or the *LiveHelp* online service expressed satisfaction with the service they received and with CIS itself. Greater levels of satisfaction were found among those with higher levels of education and self-efficacy, females, persons age 40 or under, and whites. Nearly all users said they would recommend CIS to someone else in the future, and an equal number said they would recontact the Service if they had other questions.

Satisfaction was also measured in reports from user experience on three dimensions: whether user expectations were met, user's level of trust in the information they received, and how users rated the knowledge of the Information Specialist with whom they communicated. Most CIS users said their expectations for their contact were met or exceeded, and about four-fifths said they had a high degree of trust in the information they received. Overwhelmingly, users said that they thought that the

Information Specialist who handled their inquiry was knowledgeable, and a little over half said the specialist was very knowledgeable.

Even though CIS users' reports of overall satisfaction and the three satisfaction dimensions were quite high, the percent of users who reported the highest ratings for two of the satisfaction dimensions was lower than the percent of CIS users who gave the highest satisfaction rating overall. CIS users' level of education and, to a lesser degree, age and race/ethnicity influenced their satisfaction. Fewer persons with a high school education or less felt their expectations for their CIS contact had been met and that the Information Specialist was very knowledgeable. It is possible that the content being provided by CIS is more complex or the presentation more sophisticated than appropriate for less educated users resulting in their slightly lower reports of satisfaction. Greater attention to the needs of less educated users may further raise CIS users' overall satisfaction with the Service and specifically increase the likelihood that their expectations for their CIS contact are met.

CIS users age 40 and under and Hispanics were the most likely to report the highest level of satisfaction regarding their expectations for their contact with CIS and the Information Specialists' knowledge. This survey assessed satisfaction among users, but did not collect information on the reasons for why users felt satisfied or dissatisfied. Therefore, additional research would be needed to determine the source of users higher satisfaction levels and reasons for why satisfaction differed by user characteristics.

4.3 CIS Users' Knowledge About Their Reason for Contact

An overall goal for CIS is to serve as a source of information and education about cancer and the User Survey findings show that CIS was successful in increasing knowledge about cancer and tobacco among about three-quarters of users. Nearly half of persons described themselves as only somewhat knowledgeable about cancer or tobacco prior to their contact and two-fifths also reported that their knowledge had increased "a lot" following their CIS contact. Persons who were more likely to believe their knowledge increased a lot were younger (age 40 and under), had some college education, and had a relationship to cancer. The oldest users (age 61 or older) were more likely than users age 40 and under to report being very knowledgeable prior to contacting CIS. Seniors may already know the information that CIS was providing or felt less prepared to learn new information. Results indicate that CIS has been particularly effective in increasing users' knowledge about cancer and tobacco for many groups, but targeted efforts may be needed to effectively enhance CIS' educational reach to seniors.

Users' perceived knowledge about cancer or tobacco prior to and after their CIS contact also appeared to be influenced somewhat by their education level. College graduates were more likely than persons with other levels of education to report being very knowledgeable or knowledgeable prior to contacting CIS. Persons with a high school education or less were more likely than college graduates to believe their knowledge had increased a lot, due in part because they perceived themselves to be less knowledgeable prior to contacting CIS. However, those with some college were most likely to report that their knowledge had increased a lot. It may be that the information received was beyond easy comprehension for those with the lowest education levels while those with some college had enough prior knowledge about cancer or tobacco to understand and use the information they received. Perhaps CIS could more effectively educate users who are at either end of the education spectrum by tailoring conversations and materials to address the different knowledge levels of their various audiences.

4.4 CIS Users' Self-Efficacy

CIS users were asked about their self-efficacy with regard to their confidence in performing three key behaviors. All users were asked whether their contact with CIS changed their confidence in seeking more information about a cancer- and/or tobacco-related topic. Undiagnosed users were asked about changes in their confidence in understanding the causes and risk factors for cancer. Cancer patients were asked if they felt more confident in their ability to actively participate in decisions about their treatment following their CIS contact.

Increases in users' confidence were found for all three self-efficacy indicators measured in this study. Two-thirds of CIS users felt they were more confident in seeking information about cancer and/or tobacco. CIS was most effective at increasing confidence to seek more information among those highly educated users, females, younger persons (ages 40 and under), and Hispanics. Younger users were also more likely than the oldest users (61 or older) to say they were more confident about their understanding of the causes and risk factors for cancer, while the oldest users were more likely than other all other age groups to say their confidence had stayed the same. More research is needed to determine why confidence to perform these three behavioral indicators following their CIS contact varies by education, sex, age, and race/ethnicity.

While there may be opportunities for CIS to increase users' confidence in seeking cancer information, the finding that about one-third of users said their confidence was the same following their CIS contact does not necessarily indicate a lack of success on CIS' part. Users who were also asked questions about their confidence to perform other behaviors, reported similar levels of confidence in their ability to actively participate in treatment decisions and, to a lesser degree, confidence in understanding

the causes and risk factors for cancer. About one-third of users did not have a personal relationship to cancer and a quarter of all users contacted CIS for a reason other than tobacco, clinical trials, or assistance in communicating with health professionals. It is possible that those who reported no change in their confidence to perform these three behaviors may not have felt these actions to be salient or needed.

4.5 Intention and Behavior

CIS successfully influenced users' intentions and behaviors related to cancer or tobacco use. Nearly three-quarters of CIS users reported that they had used the information they received from CIS to have a conversation with their health professional or they indicated that they plan to do so. A little over half of users who had already talked to their health professional said the CIS information had helped them a lot. CIS was also particularly effective in influencing smokers' positive intentions and behavioral changes related to their tobacco use. Nearly all smokers reported having quit, cutback, or planned to quit or cutback on smoking. Almost all smokers who had already cutback said that they planned to quit. It appears that those contacting CIS for smoking cessation assistance may have already committed to reducing or eliminating their tobacco use and their contact with CIS was effective in helping them achieve their goals. These results bode well for program goals of providing proactive smoking cessation counseling to smokers who want to quit and for reaching out to smokers who are contemplating changing their tobacco use, but have not yet made a decision to do so.

Persons who received information about clinical trials also reported positive intentions and behaviors following their CIS contact. A little more than one-third of users reported that they had followed up to inquire about their eligibility to participate in clinical trials and four-fifths of those who had not yet inquired about their eligibility intended to do so. A small group of users did not intend to find out if they were eligible for a trial; some of whom said they needed more information. Nearly half of users who contacted CIS for themselves and received information about clinical trials said that their contact had led them to seek more information about clinical trials. Younger users were more likely than those ages 61 or older were more likely to seek additional information. People who did not plan to seek additional information frequently said that they did not have enough information, had not read information they received, or were unaware of how to follow up after their CIS contact. While CIS is active in providing clinical trials information, there may be opportunities to more effectively provide users with the knowledge or resources to inquire about their eligibility to participate in clinical trials or continue their information-seeking after their CIS contact.

Few differences were found among users with regard to their intentions or actions to make healthful behavioral changes. Those with a personal relationship to cancer (self, friend or family member

diagnosed) were more likely than those with no personal relationship to cancer to have discussed the information they received from CIS with their doctor or another health professional. Persons contacting CIS about lung cancer were less likely than those contacting for other cancers to have discussed the information they received with a health professional since their contact with CIS, and they were more likely to say they did not intend to do so. Hispanics were more likely than persons of other races or ethnicities to have already spoken with a health professional about the CIS information they received.

4.6 Variations by Characteristics of Users

In addition to differences in examining the User Survey results by the key areas of expected impact on users, such as their increased cancer knowledge, some interesting variances were found by selected user characteristics. The following sections present the patterns that emerged.

4.6.1 Persons With and Without a Relationship to Cancer

CIS was effective in providing information to users with a personal relationship to cancer. In comparison with persons with no relationship to cancer, patients or persons contacting CIS about a friend or family member with cancer were more likely to say their contact with CIS had significantly increased their knowledge. They were more likely than persons with no relationship to cancer to use the information they received in their CIS contact to have a conversation with their doctor or another health professional. They also reported that they felt more confident in their ability to seek more information. Approximately the same proportion of users with and without a personal relationship to cancer said they were satisfied with the CIS, and more persons with a personal relationship to cancer said they were very satisfied. It may be that the relevance of cancer in their lives sparked more in-depth and salient interaction with the Information Specialist. Whatever the case, CIS appears to be most effective with those who most need its services.

While persons with no personal relationship to cancer also rated the Service very highly and reported many positive effects following their CIS contact, findings indicate that these users, representing a little over one-third of all users, may have needs that could be more adequately addressed by CIS. As mentioned above, they reported lower levels of increased knowledge following their CIS contact and they were more likely to say that their knowledge had not increased at all. It is possible that persons not affected by cancer are less experienced health information seekers and may be less sophisticated in formulating questions or understanding the information they received. In turn, this may contribute to their lowered sense of confidence in seeking more cancer information than persons with a personal

relationship to cancer. It may also be true that the types of questions asked by persons with no relationship to cancer are less often within the bounds of CIS' mission than inquiries made by cancer patients and their family members or friends. CIS could examine their service model and consider whether the needs of information seekers who are not affected by cancer are being served as effectively as those with a personal relationship with cancer.

4.6.2 Race/Ethnicity

CIS' effect on users' knowledge, confidence, or intention to perform specific behaviors and their satisfaction with the service provided was fairly consistent across racial and ethnic groups, although a few differences were noted. Whites were more likely than African Americans to say they were very satisfied, and African Americans were more likely than whites to say they were dissatisfied or very dissatisfied.¹¹

On several dimensions, Hispanic users were more positive about CIS than those of other racial/ethnic groups. A little over half of Hispanics reported their knowledge had increased a lot following their CIS contact, while just over one-third of whites said this. They were more likely than those in other racial or ethnic categories to report feeling more confident in seeking information about cancer; they also felt more confident than whites about understanding the causes and risk factors for cancer. Hispanics were more likely than persons of other races or ethnicities to have already spoken with a health professional about the CIS information they received. Given that CIS has not undertaken consistent efforts to specifically target the Hispanic community as cancer information seekers, the extent of positive responses from this group is notable. To capitalize on its success within this community, CIS could seek participation in initiatives such as the current effort underway to introduce a cancer message on Telemundo, a television network targeting Spanish-language consumers.

4.6.3 Age

Younger users, those age 40 or under, were less likely than the oldest group of users (age 61 or older), to report being very knowledgeable prior to their contact with CIS. They were more likely than the older group to say that their contact with CIS had increased their knowledge a lot, and they also felt more confident in their ability to seek additional cancer or tobacco information. With regard to overall satisfaction and the dimensions of satisfaction measured in this study, younger users were more likely

¹¹ This finding must be considered with some caution as only 6% of all users said they were dissatisfied or very dissatisfied and the number of African American users (n=16) who felt this way was very small.

than older users to report that they were very satisfied, that their expectations for their contact had been exceeded, and that the Information Specialist who assisted them was very knowledgeable. Clearly CIS is succeeding in increasing the knowledge of younger users; however, more assistance may be needed for older adults who already felt very knowledgeable prior to their contact and did not feel that their CIS contact had increased their knowledge or provided them with greater confidence or understanding. More research with older adults is needed to reveal how CIS can serve them more effectively.

4.6.4 Education

Level of education was found to influence many study outcomes of interest. Broadly speaking, better educated users reported more positive outcomes on a range of satisfaction dimensions. College graduates and persons with some college were more likely than persons with a high school education to report being very satisfied with their CIS contact and that they trusted the information they received a lot. They were more likely than persons with other education levels to report that their expectations had been exceeded. College graduates also reported being more knowledgeable in advance of their CIS contact and were less likely than persons of other education levels to report more confidence in understanding the causes and risk factors for cancer, perhaps because they already felt confident in the cancer knowledge.

Persons with a high school education not only reported the lowest levels of knowledge prior to their CIS contact, they also were more likely to report being dissatisfied with their CIS contact or to report negative study outcomes. While the percentage of users who were dissatisfied or very dissatisfied with their CIS contact was very small (6%), persons with a high school education were more likely than those with higher levels of education to report that they were dissatisfied with their CIS contact. With regard to the various satisfaction measures included in this study, those with high school educations were least likely to report that their expectations for their contact had been exceeded or that the information they received was trustworthy. They were more likely than those with some college to report feeling less confident in their ability to seek additional cancer information following their CIS contact. Although satisfaction levels were very high and many positive outcomes were found in this study overall, more efforts may be needed to target persons with lower education levels to effectively meet their information needs and empower them to become more confident in adopting healthful behavioral changes. Again, more research could be conducted to understand why those with less education were less satisfied.

4.6.5 Reason for Contact

Characteristics of users differed according to their reason for contact. Users contacting for information about tobacco were typically calling for themselves, were not diagnosed with cancer, were age 50 or younger, were more likely to have a high school or less education, and compared with all CIS users, were more often African American or Hispanic, although most tobacco users were white. Conversely, respondents contacting CIS for clinical trials information were nearly equally contacting for themselves or for a family member or friend, had a personal relationship to cancer, were more likely to have a college degree or higher level of education, were an older population (age 51 or older), and did not vary with regard to race when compared to all CIS users. Of those contacting CIS for help communicating with a health professional, they were more often contacting for themselves, had either been diagnosed with cancer themselves or had a family member or friend who was diagnosed, typically had at least some college or more, were age 60 or younger, and did not vary from all CIS users with regard to race/ethnicity.

Tobacco users differed from other CIS users in that they were more likely to not have a personal relationship to cancer, and to be younger or less well-educated. While findings did not show that tobacco users were less satisfied than other types of users overall, persons with no personal relationship to cancer and those who were less well-educated were less satisfied with the Service. CIS may want to keep these user characteristics in mind in considering how to refine efforts for providing cancer information and resources and smoking cessation support to tobacco users.

4.6.6 Summary

Results from the 2003 User Survey illustrate that persons who have contacted CIS for cancer- or tobacco-related information derived many benefits from the interaction. Overall, CIS users were satisfied with their encounter and felt that their information needs were being met. These positive reports reflected many favorable impacts for users including increased knowledge about cancer and/or tobacco issues, greater confidence in seeking additional cancer information, greater understanding of the causes and risk factors for cancer, greater confidence in their ability to actively participating in treatment decisions, and positive intentions and/or efforts to make healthful behavioral changes. The patterns in these positive results have been described in the sections above. These patterns identify areas of strengths and possible areas for improvements, and may even predict opportunities for CIS to allocate resources to anticipate the public's future cancer information needs.

As results from this chapter note, several opportunities exist from which CIS could benefit from conducting additional research to determine the sources and reasons for differences found among users with regard to their satisfaction with CIS, perceptions of their increased knowledge following CIS contact, their confidence to perform healthy behaviors, and their intentions or actions related to reducing or eliminating their tobacco use, seeking more information about or enrolling in clinical trials, or communicating with a health professional about the information they learned from CIS.

APPENDIX A:

SURVEY INSTRUMENT

CIS USER SURVEY 2003
Questionnaire Version 7

POST-CATI TESTING CHANGES, 2003
Nov 13, 2003

Hello, may I please speak with [NAME]?

My name is [NAME] and I am calling from Westat on behalf of the National Cancer Institute about an evaluation we are conducting for the Cancer Information Service.

The study we are conducting is for the National Cancer Institute. A few weeks ago, you agreed to share your thoughts about using the Cancer Information Service. The Service includes the 1-800-4-CANCER number, the Quit Smoking Line, and the cancer.gov web site. [IF NEEDED: The Quit Smoking Line telephone number is 1-877-44-U-QUIT.] I'd like to talk with you now about your experience with the Service. Your participation in this study is voluntary and will not in any way affect the information or service you receive from the Cancer Information Service. Everything you tell me will be confidential and you are free to end the interview at any time. If there are any questions you would prefer not to answer, we can skip them. The interview will take about 10 minutes.

Do you have any questions before I begin the interview?

First I'd like to ask about all cancer organizations that you may have contacted recently.

- A1. Not counting times when you contacted the Cancer Information Service or the Quit Smoking Line, in the past 30 days, have you contacted **other** cancer organizations or websites to find information on a cancer-related topic?

YES.....	1 (GO TO QA2)
NO.....	2 (GO TO QA3)
REFUSED.....	-7 (GO TO QA3)
DON'T KNOW.....	-8 (GO TO QA3)

- A2. What other organizations or web sites did you contact during the past 30 days? [CODE ALL THAT APPLY.] [PROBE IF NEEDED: Other than cancer.gov, 1-800-4-CANCER, or the Quit Smoking Line.]

ORGANIZATIONS

AMERICAN CANCER SOCIETY	1
AMERICAN LEGACY FOUNDATION	2
AMERICAN LUNG ASSOCIATION	3
CANCERCARE.....	4
NATIONAL ALLIANCE OF BREAST CANCER ORGANIZATIONS..	5
NATIONAL COALITION FOR CANCER SURVIVORSHIP	6
SMOKE STOPPERS	7
STATE QUIT LINE	8
SUSAN G. KOMEN FOUNDATION.....	9
US TOO	10
WOMEN'S CANCER NETWORK	11
Y-ME NATIONAL BREAST CANCER ORGANIZATION.....	12

WEBSITES

MEDLINE PLUS.....	13
ONCOLINK.....	14
SMOKEFREE.GOV	15
WEBMD	16
OTHER (SPECIFY) _____	91
REFUSED.....	-7
DON'T KNOW.....	-8

[For the rest of this survey, I will only be asking about your experience with the Cancer Information Service, either online at the cancer.gov web site or by phone at either 1-800-4-CANCER or by calling the Quit Smoking Line at 1-877-44-U-QUIT.]

A3. During the past 30 days, did you access the cancer.gov web site?

YES.....	1 (GO TO QA3A)
NO.....	2 (GO TO QA5)
REFUSED.....	-7 (GO TO QA5)
DON'T KNOW.....	-8 (GO TO QA5)

A3A. How many times during the past 30 days have you accessed the cancer.gov web site? Would you say...

Once, or.....	1
More than once?.....	2
REFUSED.....	-7
DON'T KNOW.....	-8

A4. During the past 30 days, did you use the cancer.gov LiveHelp service to have an online conversation about cancer or cancer resources?

YES.....	1 (GO TO QA4A)
NO.....	2 (GO TO QA5)
REFUSED.....	-7 (GO TO QA5)
DON'T KNOW.....	-8 (GO TO QA5)

A4A. How many times during the past 30 days did you use the cancer.gov LiveHelp? Would you say...

Once, or.....	1
More than once?.....	2
REFUSED.....	-7
DON'T KNOW.....	-8

A5. During the past 30 days, did you contact the Service using either their 1-800-4-CANCER telephone number or by calling the Quit Smoking Line at 1-877-44-U-QUIT?

YES.....	1 (GO TO QA5A)
NO.....	2 (GO TO BOX AFTER QA5A)
REFUSED.....	-7 (GO TO BOX AFTER QA5A)
DON'T KNOW.....	-8 (GO TO BOX AFTER QA5A)

A5A. How many times during the past 30 days did you contact the Service by telephone? Would you say...

Once, or.....	1
More than once?.....	2
REFUSED.....	-7
DON'T KNOW.....	-8

If QA3=2, -7, or -8 and QA5=1, go to Q6 (contacted by telephone only).

If QA5=1 and QA3=1 and QA4=3, -7, or -8, go to INTRO1A (contacted by telephone and cancer.gov website, did not use LiveHelp).

If QA5=2, -7, or -8 and QA3=1 and QA4=1, read INTROB (did not contact by telephone, used cancer.gov website and used LiveHelp).

If QA5=1, and QA3=1, and QA4=1, read INTRO C (contacted by telephone, used cancer.gov website and used LiveHelp).

If QA5=2, -7, or -8 and QA3=2, -7, or -8, go to CLOSE1.

If QA5=2, -7, or -8 and QA3=1 and QA4=2, -7, or -8, go to CLOSE1.

(CLOSE 1-Thank you very much for your time but we are only conducting this survey with people who have contacted the Cancer Information Service by phone or through their LiveHelp service online.)

INTRO1A: For the rest of the survey, please think only about your experience(s) using the telephone service.

INTRO1B: For the rest of the survey, please think only about your experience(s) using the LiveHelp service to have an online conversation about cancer or cancer resources.

INTRO1C: For the rest of the survey, please think only about your experiences using the telephone service and the LiveHelp service to have an online conversation about cancer or cancer resources.

B1. Did you contact the Service to get information mainly for...

[IF FOR MULTIPLE PEOPLE, PROBE: Who would you say you were mainly calling for?]

[IF R STILL HAS DIFFICULTY CHOOSING, PROBE: For the purpose of this survey, please answer for only one person you are calling about.]

yourself,	1	(GO TO QB3)
a family member, or	2	(GO TO QB2)
a friend?	3	(GO TO QB3)
REFUSED.....	-7	(GO TO QC1)
DON'T KNOW.....	-8	(GO TO QC1)

B2. How is this family member related to you? [IF R HAS DIFFICULTY CHOOSING: For the purpose of this survey, please answer for only one person you were calling about.]

HUSBAND.....	1
WIFE	2
PARTNER.....	3
FATHER.....	4
FATHER IN LAW	5
STEPFATHER	6
MOTHER	7
MOTHER IN LAW	8
STEPMOTHER.....	9
SON	10
STEPSON.....	11
DAUGHTER	12
STEPDAUGHTER.....	13
BROTHER	14
BROTHER IN LAW	15
STEPBROTHER	16
SISTER.....	17
SISTER IN LAW	18
STEPSISTER	19
UNCLE.....	20
AUNT	21
GRANDFATHER	22
GRANDMOTHER.....	23
OTHER (SPECIFY) _____	91
REFUSED	-7
DON'T KNOW	-8

B3. (Have you/has your [RELATION/friend]) been diagnosed with cancer?

YES.....	1	(GO TO QB4)
NO	2	(GO TO QC1)
REFUSED	-7	(GO TO QC1)
DON'T KNOW	-8	(GO TO QC1)

B4. (Are you/is your [RELATION/friend]) currently receiving treatment for cancer?

YES.....	1
NO	2
REFUSED	-7
DON'T KNOW	-8

- C1. People contact the Service for different reasons. I am going to read a list of some common reasons. Please tell me if any of the following were reasons you contacted the Service.

Did you want information about tobacco or ways to quit or cut back on smoking or using other kinds of tobacco, such as chew, spit, or snuff?

YES..... 1
 NO 2
 REFUSED -7
 DON'T KNOW -8

<i>If QC1=1(respondent wanted tobacco information), ask QC1A.</i>

- C1A. Were you specifically seeking information about...

	YES	NO	REF	DK
a. ways to quit or cut back on smoking?	1	2	-7	-8
b. ways to quit or cut back on using other kinds of tobacco, such as chew, spit, or snuff?	1	2	-7	-8
c. other information about tobacco?	1	2	-7	-8

- C2. Did you want information to help you talk with a doctor or other health professional? [FOR EXAMPLE, ONCOLOGIST, SURGEON, RADIATION THERAPIST, NURSE, MEDICAL TECHNICIAN, SOCIAL WORKER, ETC.]

YES..... 1
 NO 2
 REFUSED -7
 DON'T KNOW -8

- C3. [When you contacted the Service] Did you want to talk about or confirm information you received from a doctor or health professional?

YES..... 1
 NO 2
 REFUSED -7
 DON'T KNOW -8

- C4. [When you contacted the Service] Did you want information about clinical trials such as screening, prevention, treatment, or other types of trials?

YES..... 1
 NO 2
 REFUSED -7
 DON'T KNOW -8

C5. Did you contact the Service for any other reason?

YES.....	1
NO	2
REFUSED	-7
DON'T KNOW	-8

C5A. What was that reason?

<i>If QC4=1 (respondent called for information about clinical trials) go to D1. Else, go to QC6.</i>
--

C6. When you contacted the Service, did you receive information about cancer clinical trials such as screening, prevention, treatment, or other types of clinical trials?

YES.....	1
NO	2
REFUSED	-7
DON'T KNOW	-8

D1. Now I'd like to talk with you about your overall experience with the Service.

Think about what you expected or hoped to get from your contact with the Cancer Information Service. Overall, were your expectations...

Met,.....	1
Exceeded, or	2
Not met?	3
REFUSED	-7
DON'T KNOW	-8

D2. In general, would you say the (person/people) you worked with (was/were)...

Very knowledgeable,.....	1
Knowledgeable,	2
Somewhat knowledgeable, or.....	3
Not at all knowledgeable?	4
REFUSED	-7
DON'T KNOW	-8

D3. At this time, how much do you feel you can trust the information that you received? Do you feel you can trust the information...

A lot,.....	1
Somewhat,	2
A little, or.....	3
Not at all?	4
REFUSED	-7
DON'T KNOW	-8

D4. Overall, how satisfied are you with the Service? Would you say that you are...

Very satisfied,.....	1
Satisfied,	2
Dissatisfied, or	3
Very dissatisfied?	4
REFUSED	-7
DON'T KNOW	-8

<i>If QA4=1 (used LiveHelp), ask QD5. Else, go to QD7.</i>
--

D5. Earlier you told me that you had accessed the cancer.gov LiveHelp service to have an online conversation about cancer or cancer resources. During your LiveHelp discussion(s), did you receive any links to web pages for cancer information?

YES.....	1	(GO TO QD6)
NO	2	(GO TO QD7)
REFUSED	-7	(GO TO QD7)
DON'T KNOW	-8	(GO TO QD7)

D6. How satisfied are you with the links you received? Would you say you are ...

Very satisfied,.....	1
Satisfied,	2
Dissatisfied, or	3
Very dissatisfied?	4
DID NOT ACCESS LINKS	5
REFUSED	-7
DON'T KNOW	-8

D7. Following your contact(s), were you expecting to receive any materials by mail from the Service?

YES.....	1	(GO TO QD7OV)
NO	2	(GO TO QD10)
REFUSED	-7	(GO TO QD10)
DON'T KNOW	-8	(GO TO QD10)

D7OV. Have you received these materials?

YES.....	1	(GO TO QD8)
NO	2	(GO TO QD10)
REFUSED	-7	(GO TO QD10)
DON'T KNOW	-8	(GO TO QD10)

D8. Overall, how satisfied are you with the materials you received by mail? Would you say that you are...

Very satisfied,.....	1	(GO TO QD10)
Satisfied,	2	(GO TO QD10)
Dissatisfied, or	3	(GO TO QD9)
Very dissatisfied?	4	(GO TO QD9)
HAVE NOT READ MATERIALS	5	(GO TO QD10)
REFUSED	-7	(GO TO QD10)
DON'T KNOW	-8	(GO TO QD10)

D9. Why are you dissatisfied with the materials? (CODE ALL THAT APPLY.)

NOT RELATED TO REASON I HAD CALLED.....	1
DIFFICULT TO UNDERSTAND	2
DID NOT RECEIVE ALL MATERIALS REQUESTED	3
OTHER (SPECIFY)	91
REFUSED	-7
DON'T KNOW	-8

D10. Since you last contacted the Service, have you suggested that someone you know also contact the Service?

YES.....	1
NO	2
REFUSED	-7
DON'T KNOW	-8

D11. In the future, do you think you would recommend the Service to someone else?

YES.....	1
NO	2
REFUSED	-7
DON'T KNOW	-8

D12. In the future, if you have other questions, would you contact the Service again?

YES.....	1
NO	2
REFUSED	-7
DON'T KNOW	-8

D13. Before your contact(s) with the Service, how would you describe your knowledge about [(cancer)/(and) (the harmful effects of tobacco)]? Would you say you were...

Very knowledgeable,.....	1
Knowledgeable,	2
Somewhat knowledgeable, or.....	3
Not at all knowledgeable?	4
REFUSED	-7
DON'T KNOW	-8

D14. Do you feel that your contact(s) increased your (cancer knowledge)/[(knowledge about (cancer and) the harmful effects of tobacco)]...

A lot,	1
Somewhat,	2
A little, or.....	3
Not at all?	4
REFUSED	-7
DON'T KNOW	-8

D15. How much of the information you received during your contact(s) with the Service was new to you? Would you say...

All or most of it,	1
Some of it,	2
A little of it, or	3
None of it?	4
REFUSED	-7
DON'T KNOW	-8

If QB1=1 and QCIA (QSMOKE) = 1 or QCIA (QUITTOB) = 1 (contact for self and contact about quitting smoking or quitting other form of tobacco), go to E1. Else, go to box after QE6.

TOBACCO USER RESPONDENTS ONLY

E1. Earlier you said that one of the reasons you contacted the Cancer Information Service at either the 1-800-4-CANCER number or the Quit Smoking Line was to get information about [ways to quit or cut back on smoking (and)/ways to quit or cut back on tobacco use such as chew, spit, or snuff]

If QC1A (QSMOKE) = 1 and QC1A (QUITTOB) = 1, read:

For these next questions, please think only about quitting or cutting back on smoking.

Which of the following best describes your decisions about (smoking/using tobacco)? Would you say that before you contacted the Service you had...

- | | |
|--|----------------|
| Already quit, | 1 (GO TO QE5) |
| Already cut back, | 2 (GO TO QE2) |
| Wanted to quit or cut back but hadn't
done it yet, or | 3 (GO TO QE2) |
| you had not yet made a decision? | 4 (GO TO QE2) |
| OTHER (SPECIFY) | 91 (GO TO QE2) |
| REFUSED | -7 (GO TO QE2) |
| DON'T KNOW | -8 (GO TO QE2) |

E2. I'd like to ask about any changes you might have made since your contact with the Service. Since your contact, have you...

- | | |
|--|----------------|
| Quit (smoking/using tobacco), | 1 (GO TO QE5) |
| Cut back on (smoking/using tobacco), or.... | 2 (GO TO QE3) |
| Are you planning to quit or cutback on
(smoking/using tobacco)..... | 3 (GO TO QE4) |
| HAS NOT MADE ANY CHANGE | 4 (GO TO QE3) |
| OTHER (SPECIFY) | 91 (GO TO QE3) |
| REFUSED | -7 (GO TO QE6) |
| DON'T KNOW | -8 (GO TO QE6) |

E3. Do you plan to quit (smoking/using tobacco)?

- | | |
|------------------|----------------|
| YES..... | 1 (GO TO QE4) |
| NO | 2 (GO TO QE6) |
| REFUSED | -7 (GO TO QE6) |
| DON'T KNOW | -8 (GO TO QE6) |

E4. Have you set a date to quit (smoking/using tobacco)?

YES.....	1
NO	2
REFUSED	-7
DON'T KNOW	-8

E5. Did the suggestions from the Service help you (plan to) (quit/quit or cut back)?

YES.....	1
NO	2
REFUSED	-7
DON'T KNOW	-8

E6. Did the information you received from your contact with the Service change the way you think about (smoking/using tobacco)?

YES.....	1
NO	2
REFUSED	-7
DON'T KNOW	-8

If QC4=-1 (called for information about clinical trials), or if QC6=1 (received information about clinical trials), go to F1INTRO.

Else, if QB1=1 (calling for self), go to QF9. If Q6?1 (calling for someone else), go to QF13A.

If QB1=2 or 3 (contacted for family member or friend and QC4=1 (called for information about clinical trials), go to QF13A.

TREATMENT AND CLINICAL TRIAL RESPONDENTS ONLY

FINTRO. Earlier you said that you (contacted the Cancer Information Service to get information about clinical trials such as screening, prevention, treatment or other types of trials]/received information about clinical trials such as screening, prevention, treatment, or other types of trials, from the Cancer Information Service).

If QB1=1 (contact for self) and QC4=1(called for information about clinical trials), go to QF2. Else, continue with QF1.

F1. Before you contacted the Cancer Information Service, were you aware that clinical trials were available as an option for some people?

YES.....	1
NO	2
REFUSED	-7
DON'T KNOW	-8

If QB1=1 (contact for self), continue with QF2. Else, go to QF13A.

F2. Has the information you received from the Cancer Information Service led you to seek more information about a clinical trial?

YES.....	1	(GO TO F3)
NO	2	(GO TO QF5)
REFUSED	-7	(GO TO QF5)
DON'T KNOW	-8	(GO TO QF5)

F3. Have you found out whether or not you are eligible to participate in a clinical trial?

YES.....	1	(GO TO QF3OV)
NO	2	(GO TO QF4)
REFUSED	-7	(GO TO QF4)
DON'T KNOW	-8	(GO TO QF4)

F3OV. Were you eligible?

YES.....	1	(GO TO QF6)
NO	2	(GO TO QF9)
REFUSED	-7	(GO TO QF9)
DON'T KNOW	-8	(GO TO QF9)

F4. Do you plan to find out if you are eligible for a clinical trial?

YES.....	1	(GO TO QF9)
NO	2	(GO TO QF7)
REFUSED	-7	(GO TO QF7)
DON'T KNOW	-8	(GO TO QF7)

F5. What are the reasons you have not looked into clinical trials? [PROBE: Any other reasons?]

HAVEN'T HAD A CHANCE TO TALK WITH DOCTOR	1
DON'T WANT TO.....	2
DON'T WANT TO BE A GUINEA PIG	3
NOT SURE TRIAL IS AVAILABLE	4
POSSIBLE BAD SIDE EFFECTS	5
FINANCIAL STRAIN/CHILD CARE.....	6
INFORMATION TOO TECHNICAL.....	7
FAMILY NOT SUPPORTIVE.....	8
NO EVIDENCE I WOULD BENEFIT	9
DOCTORS MORE CONCERNED WITH SCIENCE THAN PATIENTS	10
NOT ELIGIBLE TO PARTICIPATE.....	11
HEALTH INSURANCE DOESN'T COVER COSTS.....	12
OTHER (SPECIFY)	91
REFUSED.....	-7
DON'T KNOW	-8

Go to QF9.

F6. Have you enrolled in a clinical trial?

YES.....	1	(GO TO QF9)
NO	2	(GO TO QF8)
OTHER (SPECIFY)	91	(GO TO QF9)
REFUSED	-7	(GO TO QF8)
DON'T KNOW	-8	(GO TO QF8)

F7. What are the reasons you do not plan to find out? [PROBE: Any other reasons?]

HAVEN'T HAD A CHANCE TO TALK WITH DOCTOR	1
DON'T WANT TO.....	2
DON'T WANT TO BE A GUINEA PIG	3
NOT SURE TRIAL IS AVAILABLE	4
POSSIBLE BAD SIDE EFFECTS	5
FINANCIAL STRAIN/CHILD CARE.....	6
INFORMATION TOO TECHNICAL.....	7
FAMILY NOT SUPPORTIVE.....	8
NO EVIDENCE I WOULD BENEFIT	9
DOCTORS MORE CONCERNED WITH SCIENCE THAN PATIENTS	10
NOT ELIGIBLE TO PARTICIPATE.....	11
HEALTH INSURANCE DOESN'T COVER COSTS.....	12
OTHER (SPECIFY)	91
REFUSED.....	-7
DON'T KNOW.....	-8

Go to QF9.

F8. What are the reasons you have not enrolled in a clinical trial? [PROBE: Any other reasons?]

HAVEN'T HAD A CHANCE TO TALK WITH DOCTOR	1
DON'T WANT TO.....	2
DON'T WANT TO BE A GUINEA PIG	3
NOT SURE TRIAL IS AVAILABLE	4
POSSIBLE BAD SIDE EFFECTS	5
FINANCIAL STRAIN/CHILD CARE.....	6
INFORMATION TOO TECHNICAL.....	7
FAMILY NOT SUPPORTIVE.....	8
NO EVIDENCE I WOULD BENEFIT	9
DOCTORS MORE CONCERNED WITH SCIENCE THAN PATIENTS	10
NOT ELIGIBLE TO PARTICIPATE.....	11
HEALTH INSURANCE DOESN'T COVER COSTS.....	12
OTHER (SPECIFY)	91
REFUSED.....	-7
DON'T KNOW.....	-8

F9. Since your contact(s) with the Cancer Information Service, have you discussed any of the information you received with a doctor or other health professional?

YES..... 1 (GO TO QF12)
 NO 2 (GO TO QF10)
 REFUSED -7 (GO TO QF10)
 DON'T KNOW -8 (GO TO QF10)

F10. Do you plan to discuss any of the information you received with a doctor or other health professional?

YES..... 1 (GO TO QF13A)
 NO 2 (GO TO QF11)
 REFUSED -7 (GO TO QF13A)
 DON'T KNOW -8 (GO TO QF13A)

F11. What is the main reason you don't intend to discuss this information with a doctor or other health professional?

NEED MORE INFORMATION 1
 INFORMATION CONTRADICTS/CHALLENGES WHAT THE
 DOCTOR TOLD ME 2
 INFORMATION WAS NOT GOOD/NOT HELPFUL 3
 DOCTOR IS TOO BUSY TO TALK ABOUT THIS/ DON'T WANT TO
 BOTHER THE DOCTOR 4
 NOT COMFORTABLE TALKING TO DOCTORS 5
 CONFUSED ABOUT WHO TO DISCUSS INFORMATION WITH 6
 OTHER (SPECIFY) 91
 REFUSED..... -7
 DON'T KNOW -8

Go to QF13A.

F12. How helpful was the information you received in terms of talking with a doctor or other health professional? Would you say it helped...

A lot, 1
 Somewhat, 2
 A little, or 3
 Not at all? 4
 REFUSED -7
 DON'T KNOW -8

F13A. Please tell me if your experience with the Service has affected your confidence in your ability to seek information about (a cancer-related topic)/[(and) (tobacco)]? Would you say you feel...

More confident, 1
Less confident, or 2
About the same? 3
REFUSED -7
DON'T KNOW -8

If QB =1 (calling for self) and QB3 =1(has cancer), go to QF13C. If QB=1 (calling for self) and QB3=2, -7, or -8 (does not have cancer, or refused, or don't know), ask QF13B. Else, ask QF14.

F13B. Regarding your ability to understand the causes of cancer or potential risk factors for cancer, would you say your experience with the Service has made you feel...

More confident, 1
Less confident, or 2
About the same? 3
REFUSED -7
DON'T KNOW -8

F13C. Regarding your ability to actively participate in (your/your RELATION'S) treatment decisions, would you say your experience with the Service has made you feel...

More confident, 1
Less confident, or 2
About the same? 3
REFUSED -7
DON'T KNOW -8

Go to F14.

F14- Those are all the questions I have for you. Do you have any questions or comments?

YES, HAS COMMENTS, 1
NO, HAS NO COMMENTS 2

COMMENTS: _____

Your feedback on the Cancer Information Service will be very helpful and I would like to thank you very much for your time.

APPENDIX B:

WESTAT INTERVIEWER AND CIS INFORMATION SPECIALIST

RECRUITING SCRIPT

**2003 CIS USER SURVEY
CONFIDENTIALITY SCRIPTS FOR WESTAT INTERVIEWERS**

LIVE PERSON SCRIPTS

“Can we say that National Cancer Institute is calling?”

YES – (GO TO INTRO 1)

NO – (GO TO INTRO 2)

INTRO 1

Use if a live person (not the respondent) answers phone and when respondent is asked for, the person asks, “Who may I say is calling?” and we have okay to say that NCI is calling.

My name is [NAME] and I’m calling from Westat on behalf of the National Cancer Institute about an evaluation we are conducting for the Cancer Information Service.

INTRO 2

Use if a live person (not the respondent) answers phone and when respondent is asked for, the person asks, “Who may I say is calling?” and we **do not have** okay to say that NCI is calling.

My name is [NAME] and I’m calling from Westat, a social science research firm, about an evaluation we are conducting.

If the live person (not the respondent) asks for additional information, provide the following information.

This is an evaluation about an information service [NAME] contacted recently.

ANSWERING MACHINE MESSAGES

‘If the need arises, do we have your permission to leave a message about the Cancer Information Service Survey?’

YES –MESSAGE, OKAY TO MENTION NCI

(GO TO INTRO 3)

YES –MESSAGE, DO NOT MENTION NCI

(GO TO INTRO 4)

NO –MESSAGE

DO NOT LEAVE MESSAGE

INTRO 3

Read if an answering machine is reached and respondent has indicated it is okay to say NCI is calling.

I am calling for [NAME]. This is [NAME] calling from Westat, a research firm in the Washington, DC area. We are calling about an evaluation we are conducting on behalf of the National Cancer Institute’s Cancer Information Service. We will call back within the next day or two. If you would like to set up a time for us to call you back, please contact Westat’s toll-free number 1-888-807-5917 and give your name, telephone number, and the date and time you would like to be called. Thank you.

INTRO 4

Read if an answering machine is reached and respondent has indicated it **is not okay** to say NCI is calling.

I am calling for [NAME]. This is [NAME} calling from Westat, a social science research firm in the Washington, DC area. We are calling about an evaluation we are conducting. We will call back within the next day or two. If you would like to set up a time for us to call you back, please contact Westat's toll-free number 1-888-807-5917 and give your name, telephone number, and the date and time you would like to be called. Thank you

CIS RECRUITING SCRIPT

The National Cancer Institute is evaluating this Cancer Information Service by contacting about 2,500 (callers/users) to ask their opinions. Your thoughts are important and will help improve the service provided to people like you. If you agree to participate and you are randomly selected from the group of volunteers for the survey, you will be contacted within the next 30 days by an independent research firm.

The 10 minute interview is voluntary and strictly confidential. Neither names nor telephone numbers will be associated with answers, and all results will be reported as a whole. Also, names and telephone numbers will not be disclosed to any individual or organization. May we include you?

APPENDIX C:

CIS ELECTRONIC CALL RECORD FORM (ECRF)

PAPER CRF

Form approved: CMB No. 0925-0208
 expires 11/30/06

CIS region

Staff I.D.

Date

Point of Access

Resources Used

Notes:

Type of User

Subject of Interaction

Followup Actions

Cancer Site/Type

Special Codes

Response

Primary Language Used

12/01/03

Customer Service and Demographics

May I ask you a few questions to help us evaluate our program and see who we are serving?
Your responses will be completely confidential. (use coding sheet)

Public reporting burden for this collection of information is estimated to vary from 1 to 2 minutes per response, with an average of 90 seconds per response. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: Project Clearance Office, National Institutes of Health, Room 2-106, 6701 Rockledge, Bethesda, MD 20892.

Have you used our service before?

0 Hang up, prank, wrong number 1 Yes 2 No 3 Don't Know 6 Not able to ascertain 8 Refusal 9 Did not ask ☐
(Live-Help use only)

How did you find our number to call? (use coding sheet)

What is your home/work ZIP code?

08 Refusal 11 South America 14 Other -
09 Did not ask 12 Europe 96 Not able to ascertain (Live-Help use only)
10 North America 13 Asia 99 Hang up, prank, wrong number

What is your age? (enter age)

96 Callers age 96 or older 97 Not sampled 98 Refusal 99 Did not ask

Are you female or male?

1 Female 2 Male 7 Not sampled 8 Refusal 9 Did not ask ☐

Which of these categories best describes you? (read categories 100 and 200)

100 Hispanic or Latino 200 Not Hispanic or Latino 997 Not sampled 998 Refusal 999 Did not ask

I am going to read another set of categories. Which of these categories best describes you?

(read categories 100-500 and refer to cluster codes as appropriate)

100 American Indian or Alaska Native 500 White
200 Asian 997 Not sampled
300 Black or African American 998 Refusal
400 Native Hawaiian or Other Pacific Islander 999 Did not ask

What is the highest level of education you have completed? (read categories 1-6)

1 Grade school 3 High school graduate 5 College graduate 7 Not sampled 9 Did not ask ☐
2 Some high school 4 Some college 6 Post-graduate 8 Refusal

Is there anything else I can help you with?

Thank you for calling the Cancer Information Service. Please call us again if you have other questions.

CALLER IDENTIFICATION

☐ Mr.
☐ Ms.
☐ Mrs.
☐ Dr.

Name: First Name Last Name

Organization:

Address:

-
City State ZIP

County E-mail

Phone Number: -
Area Code

Alt. Phone: -
Area Code

Fax: -
Area Code

12/01/03

APPENDIX D:

INTERVIEWER TRAINING MATERIALS

CIS USER SURVEY INTERVIEWER DRAFT TRAINING AGENDA

DAY	SESSION	TIME	LENGTH	SESSION NAME	INTERVIEWER/TRAINEE MATERIALS
1	1	9:00 - 9:30	30 min.	Introduction/Background & Types of Interviews	
	2	9:30 - 10:10	40 min.	Interactive 1:Self, Cancer, Clinical Trial Caller	
		10:10 - 10:25		15 min. Break	
	3	10:25 - 11:00	35 min.	Interactive 2: Self, Tobacco User	
	4	11:00 - 12:00	1 hr.	Contact Procedures	
		12:00 - 12:30		30 min. Lunch	
	5	12:30 - 1:15	45 min.	Sensitivity Session	
	6	1:15 - 1:40	25 min.	Refusal Avoidance	
	7	1:40 - 2:10	30 min.	Interactive 3: Calling for Family Member, has cancer	
		2:10 - 2:25		15 min. Break	
	8	2:25 - 2:55	30 min.	Question & Answers, Information Letter, Problem Sheet, Intvr. Questions	Q & A's /Info.Letter/Problem Sheet
	9	2:55 - 5:00	2 hrs. 5 min	Role Plays	Role Plays (1-6)

CIS User Survey
Sensitivity and Special Circumstances Involved in Interviewing
Respondents Dealing with Cancer-Related Issues

October 23, 2003

Introduction

We are conducting a survey with people who have contacted the Cancer Information Service (CIS) by calling either 1-800-4-CANCER or the National Cancer Institute's Quit Smoking Line (1-877-44-U-QUIT) or by visiting www.cancer.gov, then clicking on the *LiveHelp* icon to have a live online conversation with an Information Specialist. The respondents for this study have already been asked to participate in the survey by the Cancer Information Service have agreed to do so.

People contact the CIS for many different reasons, including the following:

- They have been diagnosed with or are being treated for cancer;
- A family member or friend has been diagnosed with or is being treated for cancer;
- They have symptoms of cancer and want to know what to do next;
- A family member or friend has just died from cancer and they need help coping with the death;
- They would like to quit smoking or using tobacco and need information or support; or
- They are seeking information on clinical trials.

As you conduct the interviews with people who have contacted the CIS, you will be hearing these reasons, along with many others. You will be speaking with all types of people, including the elderly, people who are sick, and people who are dying or fear that they may be dying. It is because this survey is about cancer that you need to be especially sensitive to the people you speak with on the phone.

The purpose of this session is to make you aware of some situations you may face while working on this project and to help you know how best to handle them. Before discussing specific situations that you may encounter, we need to talk about your role as an interviewer for this project.

Role of the Interviewer

As an interviewer, you must remember that your main role is to complete the survey with the respondent. Of course, many experienced interviewers know that respondents will sometimes make comments, provide lengthy answers to yes/no questions, share personal information beyond what the survey is asking, and even ask the interviewer for advice or an opinion. It is always difficult to know how best to deal with these situations. However, when you are dealing with a sensitive topic such as cancer, being prepared in advance with an appropriate response is of the utmost importance. Such advance planning will help increase the likelihood that you can complete an interview, even in a sensitive or difficult situation.

Your job is to conduct the interview. You are not a Cancer Information Specialist (although some respondents may think you are), nor are you a therapist. Therefore, you must **never give advice of any kind** to a respondent, even if he or she specifically asks you for your opinion or advice. You also must **never share your own personal experiences with the respondent**. This may be tempting because you may have been diagnosed with cancer yourself or have had a family member or friend who has been diagnosed and you can relate to what the respondent is going through.

For this study, the easiest and most appropriate way to avoid responding inappropriately is to tell the respondent that you work for a research company called Westat, which NCI hired to evaluate the service that the respondent used. Then tell the respondent that the Cancer Information Service is the most appropriate resource to answer their cancer-related questions or provide cancer information. Give the respondent the CIS telephone number, 1-800-4-CANCER and/or the NCI web site, www.cancer.gov (the number and web site are on your FAQ sheet), and advise that he or she contact the Cancer Information Service for advice or information. The CIS

is staffed with Cancer Information Specialists who have had extensive training in dealing with the cancer-related issues and questions that may arise during your interviews.

As previously mentioned, you will find that many of the people you contact will assume that you work for the Cancer Information Service. This may be inconsequential in some instances, for example, when you hear respondents make comments such as, “I was so happy with the information that you sent me,” or “I really found your service helpful.” In these cases, you do not need to remind the respondent that you do not work for the CIS. At other times, however, you **must** inform the respondent that you do not work for the CIS. These include:

- When the respondent asks you for information of any kind regarding cancer;
- When the respondent asks you for advice on a cancer-related topic;
- When the respondent asks for recommendations on specific facilities, doctors, or treatments; and
- When the respondent wants to discuss materials sent by the CIS.

Remember, when any of these situations occur, inform the respondent that you work for Westat, a research company, provide the 1-800-4-CANCER telephone number or the www.cancer.gov web site, and encourage the respondent to contact the CIS by phone or by clicking the *LiveHelp* icon online and converse with a trained Cancer Information Specialist. Doing this will guarantee that you are not providing inaccurate information to a respondent who is in crisis and may need to speak with someone who has been professionally trained to deal with questions related to cancer.

You are also encouraged to make neutral statements that let the respondent know that you hear what he/she is saying and that you care. Since this survey is conducted over the telephone, you are not able to provide the respondent with physical cues (such as nodding your head) to indicate that you hear what is being said. Instead, you will have to provide verbal cues in the form of neutral statements such as the following:

- **“I’m sorry for your loss.”**

- **“I see.”**
- **“It sounds like you are going through a lot right now.”**
- **“I’m sorry you are dealing with this difficult situation.”**
- **“I’m sorry to hear that.”**

In addition, if it sounds like you need to provide the respondent with the CIS telephone number or the NCI web site, you could say something like:

- **“It sounds like you are trying to make some really tough decisions. I do not work for the Cancer Information Service, but let me provide you with their number. They will be happy to discuss these decisions with you. Their number is 1-800-4-CANCER. You can also access their *LiveHelp* option online by going to www.cancer.gov and clicking on the *LiveHelp* icon. May I please ask you the next question on the survey now?”**

Keep in mind that you never want to offer inappropriate reassurance such as, “I know how you feel,” or “everything will be okay.”

Handling Respondents’ Physical, Emotional, and Relationship Difficulties

In order to be understanding and sensitive to the respondents in this survey, it is helpful to understand some of the difficult issues that they may be facing. While these issues are very real, they should not be obstacles preventing you from conducting your interview. Each person that we are calling for this study has already given consent to participate in this evaluation and has agreed to be interviewed.

Oftentimes, you may be speaking with respondents dealing with physical illness, emotional issues, or relationship problems. Keep in mind that many respondents will be dealing with some combination of all three issues. While your role as an interviewer is to conduct the interview, you must always remember that your compassion and sensitivity to the respondents’

situations are important for effective interviewing. Let's talk now about ways in which you can best handle sensitive situations that may arise during the interview.

Physical Illness

Some of the people you will interview have cancer and may be receiving treatment. Treatment for cancer may involve surgery, chemotherapy, radiation, the use of drugs, and often a combination of these methods. Cancer patients who are receiving treatment may feel very sick, and you must convey an understanding of what they are going through. You may want to say something like: "It sounds as though you have been through a lot." Respondents may tell you outright that they are tired, feeling sick, or need a rest. If this is the case, do not attempt to complete the survey at that point. Schedule an appointment to call back at a better time. Before ending your conversation, saying something like, "I hope you will feel a bit better soon," will let the respondent know you care. In other cases, you will need to use your active listening skills and best judgment for signs of fatigue, discontent, or illness. If you perceive a respondent is not feeling well, offer to call them back later or on a different day.

Emotional Issues

People who have been diagnosed with cancer, or who have a family member or friend who has been diagnosed with cancer, typically experience a wide variety of emotions. You may be talking to respondents who feel angry, scared, overwhelmed, shocked, stressed, anxious, depressed, guilty, or lonely, or who are in denial regarding the diagnosis. These feelings are all completely normal. You need to be prepared to deal with people who are going through any or all of these emotions. For example, you may encounter a respondent who is having a bad day and feels angry. Anger is a normal response to a crisis such as cancer, and it is often displaced onto others, including you. Try to remember what a difficult time the respondent is going through and do not take their angry comments personally. Saying "I see" or "It sounds like you

have been going through a very difficult time” acknowledges the respondent’s emotional state and may help him or her feel more comfortable during the interview.

You also may encounter a respondent who begins to cry during the interview. You may need to politely and respectfully ask if he or she would like to continue or would prefer to be called back at a better time. You need to be sensitive and to provide the respondent time to recover so that the interview can proceed. A useful phrase in this situation might be simply:

- **“Take your time.”**

If you sense that the respondent seems emotionally overwhelmed and in need of support, you may want to say something like:

- **“You sound very upset. Let me give you the telephone number and the web site address for the Cancer Information Service so you can contact them when we’re finished. They will be able to help you get through this.” Then provide the CIS telephone number and the web site address.**

Relationship Problems

Accordingly, many respondents may be dealing with major changes in their relationships or their roles in those relationships. For example, you may be conducting an interview with a man whose wife has cancer, and he is dealing with the stress and uncertainty of handling many of her customary roles (for example, child care or cooking). Generally, you will be talking to a person whose spouse, parents, child, or close friend has been diagnosed with cancer. Or, your respondent may be a cancer patient who has had to shift responsibilities to other family members and feels guilty or inadequate for having to rely on other people. You may hear that a respondent feels isolated from friends or family members, either because these individuals do not know how to deal with the diagnosis and are acting awkwardly around the cancer patient. In other cases, the patient may choose to isolate him/herself from friends and family for a variety of

reasons. If a respondent indicates feeling isolated from others, suggest that he/she contact the CIS to speak with an Information Specialist, and provide that information.

Summary

In summary, the people you interview will probably be cancer patients or family or friends of people who have been diagnosed with cancer. These people may be experiencing a variety of difficult issues, including physical illness, wide-ranging emotions, and changes in their relationships. When talking with respondents who are going through difficult times, it is always tempting as an interviewer to share your own personal experiences or provide advice in an attempt to relate to the respondent. However, it is extremely important for this study that you do neither. Instead, you can suggest that the respondent call the toll-free CIS telephone number 1-800-4-CANCER or click on the *LiveHelp* icon at the www.cancer.gov web site and converse with a Cancer Information Specialist who can provide information and support. Also, by making appropriate and neutral statements, you can let the respondent know that you hear and care about what he or she is saying.

Listed below are some other ways that we can handle difficult or emotional respondents:

- Give the respondent time to answer without pressure.
- Be attentive to signs of fatigue, illness, or distraction.
- For elderly respondents, speak slowly and loudly, repeat questions and response categories if necessary, break questions down into smaller sentences, reflect back what the respondent said to check for accuracy of what you heard, and politely ask the respondent to repeat him/herself if necessary.
- Make neutral statements that let the respondent know you care, but **never** provide advice, share your opinion, or offer inappropriate reassurance such as, “I know how you feel,” or “everything will be okay.”
- Provide the CIS 1-800-4-CANCER telephone number and/or the web site when a respondent explicitly asks for it or if you feel that a respondent may be

seeking support or has cancer-related questions but has not specifically asked for the number or web site.

Discussion

Now let's talk a little more about this. **ASK INTERVIEWERS THE FOLLOWING QUESTIONS:**

1. **What are cues that might tell you that the respondent is having a hard time or is feeling uncomfortable during the telephone interview? How should you handle this?**

Possible examples: Quiver in voice, speaking more softly, tone of voice, sighing, balking at certain questions, crying.

2. **How do you respond to a respondent who says:**

- "I just don't know how I can take this anymore. I don't want to live anymore."

Possible response: "It sounds like you are going through a very difficult time. I would like to encourage you to contact the Cancer Information Service and talk with an Information Specialist. They can help you find ways to get through this."

- "This is my only child, and she has leukemia."

Possible response: "It sounds like this is a very difficult time for your family."

- "I am dying and they don't expect me to live through the year."

Possible response: "I'm sorry to hear that. This must be a difficult time for you. Perhaps it would help to talk with a specialist from the Cancer Information Service. I would be happy to give you that number or their web site address."

- "Can you tell me how to get more information on screening trials?"

Possible response: I don't have that information, but let me give you the phone number and the web site address to the Cancer Information Service so you can contact them when we are finished. They will be glad to provide you with this information."

- “Do you have cancer?”

Possible response: This survey is about your experiences with the Cancer Information Service. I would like to ask you the next survey question so we can be sure to capture your experience in using the Service.

3. What are some neutral statements that you have used before that were useful when dealing with respondents who are going through a difficult time?

Interviewers discuss their own statements and get ideas from one another.

CANCER INFORMATION SERVICE USER SURVEY

DEFINITIONS AND COMMON NAMES OF CURRENT CLINICAL TRIALS

Clinical trials are research studies that involve people. Each study tries to answer scientific questions and to find better ways to prevent, screen for, diagnose, or treat a disease. Six types of clinical trials are cancer screening trials, cancer prevention trials, cancer treatment trials, diagnostic trials, supportive care trials, and genetic studies.

Screening trials study ways to detect cancer. They are often conducted to determine whether finding cancer before it causes symptoms decreases a person's chance of dying from the disease. These trials involve people who do not have any symptoms of cancer.

Prevention trials study ways to reduce the risk or chance of developing cancer. Most prevention trials are conducted with healthy people who have not had cancer. Some trials are conducted with people who have had cancer and want to prevent the return (recurrence) of cancer, or reduce the chance of developing a new type of cancer.

Treatment trials are conducted with people who have cancer. They are designed to answer specific questions about and evaluate the effectiveness of a new treatment or a new way of using a standard treatment. These trials test many types of treatments, such as new drugs, vaccines, new approaches to surgery or radiation therapy, and new combinations of treatments.

Diagnostic trials study tests or procedures that could be used to identify cancer more accurately and at an earlier stage. Diagnostic trials usually include people who have signs or symptoms of cancer.

Supportive care trials (also called quality of life trials) explore ways to improve the comfort and quality of life of cancer patients and cancer survivors. These trials study ways to help people who are experiencing nausea, vomiting, sleep disorders, depression, or other effects from cancer or its treatment.

Genetic studies are sometimes part of another cancer clinical trial. The genetics component of the trial may focus on how genetic make-up can affect detection, diagnosis, or response to cancer treatment. People who participate in these trials may or may not have cancer. The goal of these studies is to help understand the role of genes in the development of cancer.

Names of Common Clinical Trials Currently in Progress (in alphabetical order):

- ALTS (Autolympocyte Therapy) Cervical Cancer Screening Trial
- Beta Carotene Chemoprevention Trials
- Breast Cancer Prevention Trial
- Breast Cancer Prevention Studies
- Chemoprevention
- NLST (National Lung Screening Trial)
- PLCO (Prostate, Lung, Colon, Ovarian)
- Prostate Cancer Prevention Trial
- SELECT (Selenium and Vitamin E) Prostate Cancer Prevention Trial
- (STAR) Study of Tamoxifen and Raloxifene Trial

ALLEVIATING SUSPICIONS/FEARS

What's this study about?

The purpose of the survey is to evaluate the Cancer Information Service, a free public service of the National Cancer Institute. People can contact trained CIS Information Specialists by calling 1-800-4-CANCER, the NCI Quit Smoking Line at 1-877-44-U-QUIT, or by clicking on the *LiveHelp* icon on the www.cancer.gov web site. NCI is interested in learning about people's experiences with the CIS to help improve their service to the public.

I called to quit smoking; I didn't call the Cancer Information Service.

The Cancer Information Service provides information about quitting smoking and other forms of tobacco to people who call their 1-800-4-CANCER telephone number and the NCI Quit Smoking Line (1-877-44-U-QUIT). We are interested in learning about your experience in learning more about ways to quit smoking or using tobacco.

I'm not interested. I don't want to buy anything.

If I may take just a minute or two of your time to explain a bit about this important evaluation sponsored by the National Cancer Institute. I'm not selling anything. This study is being conducted to gather information about the experiences of people who contact the Cancer Information Service.

How do I know the survey is legitimate? How do I know that you are really an interviewer for this survey?

If you wish, you may speak to my supervisor now, or I can give you a toll-free 800 number to call at your convenience. The number is: **1-888- 807- 5917**. (TRC Toll-Free Number)

How do I know you will keep this information confidential?

We are required by law not to reveal any information except to persons directly involved with the study. Additionally, we are required to sign a statement of confidentiality regarding all information provided by respondents. No individual responses or information that would permit the identification of any individual will be released or published. Your name will not be reported with any of the information you provide.

I had a bad experience recently with someone taking a survey, so I don't think I want to participate.

I'm sorry that your experience was a bad one. However, this is an important evaluation effort, and we hope to make your contact with us pleasant. By participating in the study, you will help us to learn more about the experiences of those using the Cancer Information Service. This is your chance to be heard.

I think this whole business is stupid. The money for this study could be spent more wisely, etc., etc.

DO NOT ARGUE WITH THE RESPONDENT. SIMPLY MAKE SHORT NEUTRAL COMMENTS TO LET THEM KNOW YOU ARE LISTENING.

MAKE A COMMENT SUCH AS: "As a government service, the Cancer Information Service is accountable to the taxpayers. Your opinions are very interesting and your answers will be important for the survey. Let's start now." [ASK THE FIRST QUESTION]

Why are you calling me? Who else are you calling?

How did you get my name/number?

Your name and telephone number were provided to us by the Cancer Information Service. When you contacted them during the last 30 days, you were invited to participate in this evaluation.

Who are you calling for this survey?

The Cancer Information Service is interested in hearing feedback from people who have used their Service in the past 30 days. The survey will be conducted with a variety of people, including cancer patients, family members or friends of people with cancer, and people seeking information about tobacco or ways to quit smoking or using other forms of tobacco. The survey will be conducted with a random sample of 2,500 people who have contacted the Cancer Information Service.

Why was your number blocked on my caller ID?

We do not block our number. However, sometimes, local telephone carriers do not display numbers from outside the calling area. We are calling from Maryland.

Why don't you call someone else?

It's important that we talk with you because rules governing the way scientific research samples are selected do not allow us to replace you with someone else. Once a person has been selected, we must talk to that person about their experiences. Otherwise, we would not get a representative picture of the national population. Your responses represent a lot of other people and you are actually speaking for them, as well as yourself.

Do I have to do this? Do I have to answer your questions?

Your participation is completely voluntary and if you don't want to answer a question you may skip over it. Your input and opinions are very important to the success of this study. Your decision to participate will in no way affect the information or service you receive from the Cancer Information Service.

I'm on the "Do not call list"/Please remove my name from your calling list.

I'm not selling anything. I work for a research company and we are not calling from a marketing list.

IF NECESSARY: The telephone calls we make are not prohibited or regulated by the Federal Trade Commission (FTC).

Explanations About Questions & Results

What is this survey about?

The purpose of the survey is to evaluate the Cancer Information Service, a free public service of the National Cancer Institute. People can contact trained CIS Information Specialists by calling either their 1-800-4-CANCER telephone number or the NCI Quit Smoking Line at 1-877-44-U-QUIT, or by clicking on the *LiveHelp* icon on the www.cancer.gov web site. NCI is interested in learning about people's experiences with the CIS to help improve their service to the public.

What kind of questions will you be asking?

The questions will mostly focus on your experience in contacting the Cancer Information Service and your satisfaction with the service you received either through the CIS 1-800-4-CANCER telephone number, the NCI Quit Smoking Line, or *LiveHelp*, their web-based service on www.cancer.gov. For example, one question asks: Overall, how satisfied are you with the Service?

Most people find the questions interesting and enjoy providing feedback about their experience with the Cancer Information Service.

Can I get a copy of the results?

I will be happy to take your name and address. We can send you a summary of the major results when they are available in August 2004. (USE CTRL/I TO COLLECT INFO)

How will the survey results be used? What will you do with this information?

The Cancer Information Service will use the survey results to evaluate the service they are providing and make changes based on the needs and satisfaction of the users of this service. The information you provide will be analyzed and summarized along with other people's responses in order to provide the Cancer Information Service with a report about the needs those who call the Service. Your name or any other identifying information will not be used in the report.

How long will this take?

Approximately 10 minutes, depending on your answers.

How can I get help to quit smoking? I have cancer, and I don't know what to do? Can you give me information on participating in a clinical trial?

UNDER NO CIRCUMSTANCES ARE YOU TO GIVE PERSONAL OPINION OR ADVICE. ANYONE REQUESTING INFORMATION ON CANCER, QUITTING TOBACCO, OR ENROLLING IN CLINICAL TRIALS SHOULD BE GIVEN THE CANCER INFORMATION SERVICE TOLL-FREE NUMBER 1-800-4-CANCER OR THE WEB SITE ADDRESS WWW.CANCER.GOV

Sponsor/For whom do you work?**Who do you work for?**

I work for WESTAT, a social science research company. Our headquarters is located in Rockville, Maryland. WESTAT conducts surveys and evaluations on many different subjects and is working with the National Cancer Institute to conduct this study.

Does Westat have a web site?

Yes, WESTAT has a web site. The address is www.westat.com

Is there a web site for this study?

No, there is not a web site setup for this study. However, if you would like more information about the sponsor of this study, the National Cancer Institute, you can access their web site at www.cancer.gov

Who is the sponsor for this study?

The National Cancer Institute

Who can I call to verify this study?

You can call the Westat project director. Her name is Meredith Grady and her telephone number is 1-800-937-8281 extension 2748.

Who can I call at the National Cancer Institute to verify the study?

You can call the Deputy Director of the Cancer Information Service. Her name is Madeline La Porta and her telephone number is 301-594-8025.

Does the project have an OMB clearance number?

Yes. The OMB clearance number is: 0925-0500-02.

APPENDIX E:

CIS USER STUDY INFORMATION LETTER



National Institutes of Health
National Cancer Institute
Bethesda, Maryland 20892

Dear Mr./Ms. _____:

The National Cancer Institute (NCI) is evaluating its Cancer Information Service (CIS), a free public service of the NCI, the Nation's primary agency for cancer research. Recently, you contacted our service and at that time, you were asked to participate in an evaluation about your experience. This letter is in response to your request for additional information about the evaluation.

As part of the NCI mission to provide the most accurate cancer information to the public, NCI has contracted with Westat, an independent research firm in Rockville, Maryland, to conduct an evaluation with about 2,500 people who contacted the CIS. The public is able to contact the CIS either by telephone at 1-800-4-CANCER, through the NCI Quit Smoking Line at 1-877-44-U-QUIT, or online through *LiveHelp*, the CIS web-based service located on the National Cancer Institute's web site at www.cancer.gov. We will use the survey findings to inform and improve the CIS, and your experience with the CIS is important to that effort.

Our evaluation is strictly confidential, and results will be reported as a whole. We will not know how any individual responded to the questions. We want to assure you that neither your name nor your address will be disclosed to any individual or organization.

For the evaluation, Westat interviewers are talking with people from across the country. They are asking questions about users' experience with the CIS. For example, one question they are asking is "Overall, how satisfied are you with the Cancer Information Service?"

If an interviewer calls you at an inconvenient time, please suggest a better time to call. If you would like to set up an appointment before someone calls, please contact Westat toll-free at 1-888-807-5917.

NCI is part of the U.S. Department of Health and Human Services and the National Institutes of Health. If you would like to learn more about the NCI, please visit our web site at www.cancer.gov. If you have any questions about your rights as a participant, please call Meredith Grady at Westat's toll-free number, 800-937-8281, ext. 2748. If you would like to talk with someone at NCI about the evaluation, please contact Madeline La Porta, Deputy Associate Director of the CIS, at 301-594-8025.

Sincerely,

Madeline R. La Porta
Deputy Associate Director
Cancer Information Service
National Cancer Institute

APPENDIX F:

CONSISTENCY CHECK TO DETERMINE RESPONDENT ELIGIBILITY

2003 User Survey

November 20, 2003

Survey Implementation Changes – Document 1 Consistency Check to Reduce Ineligible Cases

AINTRO2

The Cancer Information Service has told us that you contacted them in the past 30 days and that you agreed to share your thoughts about using the Service. There are three ways you may have contacted the Service: the 1-800-4-CANCER number, the Quit Smoking Line, and the cancer.gov web site. [IF NEEDED: The Quit Smoking Line telephone number is 1-877-44-U-QUIT.] I'd like to talk with you now about your experience with the Service. Your participation in this confidential study is voluntary and you are free to end the interview at any time, or skip any questions you would prefer not to answer. The interview will take about 10 minutes.

Add to Box A-1

If QA5=2, -7, or -8 and QA3=2,-7, or -8 (didn't use telephone, didn't use web), go to CONSISTENCY CHECK 1. If CONSISTENCY CHECK 1=2,-7,-8, go to CLOSE 1.

If QA5=2,-7, or -8 and QA3=1 and QA4=2,-7, or -8 (didn't use telephone, used web, didn't use Live Help), go to CONSISTENCY CHECK 2. If CONSISTENCY CHECK 2=2, -7, or -8, go to CLOSE 1.

CONSISTENCY CHECK 1 (NEW)

Let me double-check what you have told me because I want to make sure I have not made a mistake. You said you did not use the Cancer Information Service's 1-800-4-CANCER telephone number. Do you remember calling a telephone number recently to get information about cancer or quitting smoking or using other tobacco? You may have gotten it from a book or magazine or maybe a family member or friend told you about it. When you called the number you would have heard a recording with basic information about the Cancer Information Service and options for talking with a Cancer Information Specialist, learning about ways to quit smoking or using other tobacco, or to order information.

[PAUSE]

You also said you have not used the cancer.gov web site. Have you recently looked on the Internet for information about cancer or ways to quit smoking or using other tobacco? [If yes, do you remember using a web site that let you have an online conversation, chat, or instant message with someone about questions you had about a cancer issue or ways to quit smoking or using other tobacco? You would have clicked on an icon that said LiveHelp and it would have connected you to a screen where a Cancer Information Specialist came online and asked if you had any questions.]

[If the respondent recalls using the telephone or web services to get information about cancer, back up to QA3 and reenter the responses.]

YES = 1

N0 = 2

REFUSED = -7

DON'T KNOW = -8

CONSISTENCY CHECK 2 (NEW)

Let me double-check what you have told me because I want to make sure I have not made a mistake. You said you have used the Cancer Information Service's cancer.gov web site but you did not access the LiveHelp service to have an online conversation about cancer or cancer resources. Do you remember using a web site that let you have an online conversation, chat, or instant message with someone about questions you had about a cancer issue or ways to quit smoking or using other tobacco? You would have clicked on an icon that said LiveHelp and it would have connected you to a screen where a Cancer Information Specialist came online and asked if you had any questions.

[PAUSE]

You also said you did not call the 1-800-4-CANCER telephone number or their Quit Smoking Line. Do you remember calling a telephone number recently to get information about cancer or quitting smoking or using other tobacco? You may have gotten it from a book or magazine or maybe a family member or friend told you about it. When you called the number you would have heard a recording with basic information about the Cancer Information Service and options for talking with a Cancer Information Specialist, learning about ways to quit smoking or using other tobacco, or to order information.

[If the respondent recalls using the telephone or web services to get information about cancer, back up to QA3 and reenter the responses.]

YES = 1

N0 = 2

REFUSED = -7

DON'T KNOW = -8

APPENDIX G:

STANDARD ERROR TABLES

Table 4a.—Standard errors for characteristics of CIS users: 2004

User characteristic	All CIS users		CIS users calling for self		CIS users calling for family member or friend	
	Number	Percent	Number	Percent	Number	Percent
Total.....		†		†		†
User type						
Contacted for self.....	173.9	0.7	—	—	—	—
Contacted for family member or friend.....	174.3	0.7	—	—	—	—
Diagnosed with cancer.....	214.4	0.9	136.0	1.1	160.9	1.4
Not diagnosed with cancer.....	215.3	0.9	198.2	1.1	156.0	1.4
Reason contacted CIS						
Information about tobacco.....	94.7	0.4	93.9	0.7	54.3	0.5
Ways to quit or cut back smoking.....	88.3	0.4				
Ways to quit or cut back other tobacco.....	35.4	0.1				
Other information about tobacco.....	45.8	0.2				
Information about clinical trials.....	222.8	0.9	181.8	1.2	217.8	2.0
Help communicating with health professional.....	219.9	0.9	178.3	1.3	178.3	1.6
Other reasons for contact.....	234.4	1.0	166.9	1.2	165.9	1.5
Cancer site/type						
Breast.....	211.9	0.9	168.6	1.2	125.1	1.1
Lung.....	168.5	0.7	144.0	1.0	109.0	1.0
Prostate.....	114.0	0.5	93.2	0.7	70.4	0.7
Colorectal.....	139.4	0.6	80.8	0.6	111.5	1.1
Other cancer site(s).....	117.7	0.7	172.9	1.2	187.0	1.8
Not applicable/no cancer site specified.....	239.0	1.0	140.6	1.0	111.8	1.0
Level of education						
High school or less.....	24.0	0.1	128.3	0.8	128.9	1.1
Some college.....	25.5	0.1	134.5	0.8	131.5	1.1
College graduate or higher.....	8.7	0.0	119.7	0.8	118.7	1.1
Sex						
Female.....	47.6	0.2	187.0	0.9	176.1	1.1
Male.....	46.8	0.2	126.7	0.9	121.9	1.1
Age						
40 and under.....	88.3	0.4	137.1	1.0	141.9	1.3
41–50.....	114.3	0.5	135.1	0.9	141.2	1.3
51–60.....	106.1	0.4	118.0	0.8	122.9	1.0
61 or older.....	81.1	0.3	145.7	1.0	141.6	1.3
Race/ethnicity						
White, non-Hispanic.....	65.8	0.3	197.1	1.0	181.7	1.0
African American, non-Hispanic.....	29.5	0.1	87.0	0.6	80.3	0.8
Hispanic.....	24.8	0.1	58.2	0.4	56.7	0.5
All other races.....	66.4	0.3	82.4	0.6	65.4	0.6
Mode of contact						
Telephone.....	79.9	0.3	182.9	0.4	185.1	0.6
Live Help.....	166.2	0.7	54.2	0.4	65.9	0.6

—Not applicable.

†Not applicable; estimate of standard error is not derived because it is based on an estimate of 100 percent.

**Table 5a.—Standard errors for all CIS users by reason for contact, by selected characteristics:
2004**

User characteristic	Reason for contacting CIS					
	Information about tobacco		Clinical trials information		Help communicating with health professionals	
	Number	Percent	Number	Percent	Number	Percent
Total.....	94.7	‡	222.8	‡	219.9	‡
User type						
Contacted for self.....	91.1	2.7	179.5	1.5	178.5	2.5
Contacted for family member or friend.....	54.3	2.7	215.0	1.5	172.0	2.5
Diagnosed with cancer.....	55.6	2.5	207.8	1.5	190.3	2.4
Not diagnosed with cancer.....	79.8	2.5	178.6	1.5	150.8	2.4
Level of education						
High school or less.....	66.0	2.7	137.0	1.0	126.3	2.0
Some college.....	71.9	2.9	140.7	1.2	128.0	2.1
College graduate or higher.....	47.7	2.4	163.7	1.3	172.0	2.3
Sex						
Female.....	80.9	2.8	225.5	1.2	176.4	1.7
Male.....	65.1	2.8	127.6	1.2	119.5	1.7
Age						
40 and under.....	63.1	2.7	138.4	1.1	126.1	1.9
41–50.....	42.5	2.1	131.3	1.2	96.4	1.5
51–60.....	56.8	2.6	141.8	1.2	92.2	1.5
61 or older.....	47.3	2.2	157.3	1.3	127.4	1.9
Race/ethnicity³						
White, non-Hispanic.....	86.1	2.9	200.4	1.0	179.3	1.6
African American, non-Hispanic.....	43.8	2.1	100.9	0.9	75.3	1.3
Hispanic.....	40.4	2.0	55.3	0.5	57.5	1.0
All other races.....	‡	1.4	73.8	0.7	64.0	1.0

‡Reporting standards not met; less than 30 unweighted cases in cell.

Table 7a.—Standard errors for the percent of all CIS users (n=24,540) reporting various levels of knowledge prior to contact and the perceived effect of CIS contact on knowledge, by selected characteristics: 2004

User characteristic	Knowledge prior to contacting CIS				Increased knowledge after contacting CIS			
	Very knowledge-able	Knowledge-able	Somewhat knowledge-able	Not at all knowledge-able	A lot	Somewhat	A little	Not at all
Total	0.7	1.0	1.1	0.8	1.1	1.0	0.8	0.7
Diagnosis								
Diagnosed with cancer	0.9	1.2	1.4	1.0	1.5	1.2	0.9	0.8
Not diagnosed with cancer	1.1	1.5	1.7	1.3	1.8	1.7	1.5	1.5
Cancer site/type								
Breast	1.7	2.1	2.4	1.9	2.4	2.7	1.4	2.0
Lung	2.0	2.6	2.5	2.1	2.6	2.9	2.2	3.0
Prostate	2.7	3.4	3.9	2.4	4.2	3.6	2.9	2.2
Colorectal	2.9	3.9	4.5	2.7	4.2	3.9	‡	2.5
Other cancer site(s)	1.9	2.7	2.8	2.2	2.9	2.8	2.0	2.7
Not applicable/no cancer site specified	1.1	1.5	1.8	1.3	1.8	1.7	1.3	1.2
Level of education								
High school or less	1.1	1.6	1.8	1.4	1.9	1.7	1.3	1.3
Some college	1.2	1.4	2.1	1.3	2.1	1.7	1.3	1.3
College graduate or higher	1.5	1.7	2.0	1.1	1.8	1.8	1.3	1.4
Sex								
Female	0.8	1.1	1.3	0.9	1.3	1.2	0.9	0.9
Male	1.4	2.1	2.1	1.6	2.1	1.9	1.9	1.5
Age								
40 and under	1.3	2.2	2.1	1.5	1.9	2.1	1.4	1.3
41–50	1.3	2.2	2.3	1.8	2.0	2.2	1.6	1.6
51–60	1.6	1.9	1.9	1.6	2.1	2.0	1.6	1.3
61 or older	1.5	2.0	1.9	1.3	2.0	1.9	1.6	1.4
Race/ethnicity								
White, non-Hispanic	0.8	1.2	1.3	0.9	1.3	1.3	0.9	0.9
African American, non-Hispanic	2.2	2.9	3.3	2.1	3.1	3.2	1.7	2.5
Hispanic	‡	3.7	4.3	‡	4.0	4.5	3.1	1.9
All other races	‡	3.2	4.2	3.2	3.9	3.2	3.4	2.6

‡Reporting standards not met; less than 30 unweighted cases in cell.

Table 8a.—Standard errors for the increase in perceived knowledge following CIS contact, by level of reported prior knowledge: 2004

Knowledge prior to contacting CIS	Increased knowledge after contacting CIS			
	A lot	Somewhat	A little	Not at all
Very knowledgeable	2.5	2.7	2.0	2.5
Knowledgeable	1.9	2.2	1.3	1.5
Somewhat knowledgeable	1.7	1.6	1.2	1.1
Not at all knowledgeable	2.9	2.5	2.1	1.7

Table 9a.—Standard errors for the percent of CIS tobacco contacts for self (n=1,620) who reported a change in thinking about tobacco following CIS contact, by selected characteristics: 2004

User characteristic	Percent indicating CIS changed thinking
Total	3.4
Diagnosis	
Diagnosed with cancer.....	10.6
Not diagnosed with cancer.....	3.6
Level of education	
High school or less	4.8
Some college	5.5
College graduate or higher	‡
Sex	
Female.....	3.6
Male	6.9
Age	
40 and under.....	4.7
41–50	5.1
51–60	7.8
61 or older	‡
Race/ethnicity	
White, non-Hispanic	4.4
African American, non-Hispanic	6.6
Hispanic	5.8
All other races	‡

‡Reporting standards not met; less than 30 unweighted cases in cell.

Table 10a.—Standard errors for the effect of CIS contact on users' level of confidence, by selected characteristics: 2004

User characteristic	Confidence in ability to seek information (n=24,540)			Confidence of those not diagnosed with cancer in understanding causes/risk factors for cancer (n=7,320)			Confidence of those with cancer in actively participating in treatment decisions (n= 6,390)		
	More	Same	Less	More	Same	Less	More	Same	Less
Total percent	1.0	1.0	0.3	0.8	0.8	0.1	0.7	0.5	0.1
Diagnosis									
Diagnosed with cancer.....	1.2	1.2	‡	—	—	—	2.0	2.1	0.49
Not diagnosed with cancer.....				2.3	2.3	0.4	—	—	—
Cancer site/type									
Breast	2.5	2.4	‡	3.9	3.9	0.5	3.9	3.9	‡
Lung	3.0	2.9	‡	4.9	4.7	1.3	6.6	6.7	‡
Prostate.....	3.8	3.8	‡	9.4	9.4	†	6.1	6.1	†
Colorectal	4.0	4.0	‡	11.5	‡	†	9.8	‡	†
Other cancer site(s).....	3.0	3.1	‡	3.6	3.6	0.4	12.1	12.1	†
Not applicable/no cancer site specified.....	1.5	1.5	‡	4.9	4.9	0.9	‡	‡	‡
Level of education									
High school or less	1.7	1.8	‡	3.2	3.2	†	3.2	3.2	‡
Some college	1.2	1.9	‡	3.5	3.5	0.5	3.9	3.8	‡
College graduate or higher.....	1.8	1.8	‡	4.1	4.2	0.9	3.4	3.5	‡
Sex									
Female.....	1.1	1.1	‡	2.6	2.7	0.4	2.5	2.5	‡
Male	2.2	2.1	‡	3.6	3.5	0.9	3.3	3.4	‡
Age									
40 and under.....	1.8	1.8	‡	3.9	3.8	0.5	5.0	5.0	†
41–50	2.3	2.3	‡	4.8	4.8	†	5.1	5.0	‡
51–60	2.3	2.2	‡	3.8	3.90	0.9	3.2	3.2	‡
61 or older	1.9	2.0	‡	4.2	4.2	1.1	3.5	3.7	‡
Race/ethnicity									
White, non-Hispanic	1.1	1.0	‡	2.5	2.5	0.4	2.4	2.4	‡
African American, non-Hispanic	3.2	3.2	‡	5.5	5.5	†	5.9	5.9	†
Hispanic	3.4	3.4	‡	6.7	6.7	0.8	‡	‡	†
All other races	3.5	3.4	‡	8.7	8.8	3.2	‡	‡	‡

—Not applicable.

†Not applicable; estimate of standard error is not derived because it is based on an estimate of 0 percent.

‡Reporting standards not met; less than 30 unweighted cases in cell

Table 11a.—Standard errors for the dimensions of satisfaction with CIS contact, by selected characteristics: 2004

User characteristic	Overall satisfaction			Expectations		
	Very satisfied	Satisfied	Dissatisfied or very dissatisfied	Exceeded	Met	Not met
Total.....	1.1	1.1	0.5	0.9	1.0	0.7
User type						
Contacted for self.....	1.5	1.5	0.7	1.1	1.5	1.0
Contacted for family member or friend.....	1.6	1.6	0.7	1.6	1.5	1.1
Diagnosis						
Diagnosed with cancer.....	1.3	1.3	0.7	1.2	1.2	0.9
Not diagnosed with cancer.....	1.9	1.9	0.9	1.6	1.7	1.2
Reason contacted CIS*						
Seeking information about tobacco.....	3.2	3.3	1.1	2.7	3.0	1.8
Seeking clinical trials information	1.7	1.8	0.7	1.4	1.6	1.0
Help communicating with a health professional.....	2.2	2.2	0.7	1.9	2.1	1.3
Other reasons for contact	2.4	2.2	1.5	2.0	2.4	1.9
Level of education						
High school or less	1.8	1.8	1.1	1.6	1.9	1.5
Some college	1.9	2.0	0.8	1.7	1.9	1.1
College graduate or higher.....	2.1	2.1	0.9	1.8	1.7	1.2
Sex						
Female	1.3	1.4	0.6	1.1	1.2	0.8
Male.....	2.0	1.9	1.1	1.7	2.2	1.6
Age						
40 and under	2.2	2.1	0.8	2.0	2.1	1.3
41–50.....	2.4	2.4	1.1	2.2	2.5	1.6
51–60.....	2.1	2.1	1.0	2.0	2.1	1.3
61 or older	1.9	2.0	1.1	1.6	2.1	1.6
Race/ethnicity						
White, non-Hispanic	1.4	1.4	0.6	1.1	1.3	0.8
African American, non-Hispanic	3.3	3.3	1.5	2.6	2.9	2.2
Hispanic	3.9	4.0	2.2	4.2	4.3	2.2
All other races	3.5	3.6	2.3	3.2	3.7	3.1

Table 11a.—Standard errors for the dimensions of satisfaction with CIS contact, by selected characteristics: 2004—continued

User characteristic	Knowledge of information specialist ¹		Trust in information ²	
	Very knowledgeable	Knowledge-able or somewhat knowledgeable	A lot	Somewhat or a little
Total.....	1.1	1.1	0.8	0.8
User type				
Contacted for self.....	1.4	1.5	1.2	1.0
Contacted for family member or friend.....	1.7	1.6	1.4	1.1
Diagnosis				
Diagnosed with cancer.....	1.4	1.3	1.1	0.9
Not diagnosed with cancer.....	1.9	1.9	1.5	1.6
Reason contacted CIS*				
Seeking information about tobacco.....	3.0	3.0	2.0	1.9
Seeking clinical trials information	1.8	1.8	1.3	1.2
Help communicating with a health professional	2.0	1.9	2.0	1.8
Other reasons for contact	2.5	2.4	1.8	1.2
Level of education				
High school or less	1.9	1.9	1.6	1.4
Some college	2.1	2.1	1.4	1.2
College graduate or higher.....	2.0	1.9	1.5	1.2
Sex				
Female	1.4	1.3	1.0	0.9
Male.....	2.2	2.2	1.8	1.5
Age				
40 and under	2.2	2.2	1.6	1.6
41–50.....	2.2	2.1	1.5	1.4
51–60.....	2.2	2.2	1.8	1.6
61 or older	2.0	1.8	1.9	1.3
Race/ethnicity				
White, non-Hispanic	1.4	1.3	1.2	0.9
African American, non-Hispanic	3.2	3.0	2.9	2.5
Hispanic	4.2	4.3	3.3	3.2
All other races	3.7	3.7	3.2	2.8

Table 12a.—Standard errors for dimensions of satisfaction, by mode of CIS contact: 2004

Dimension of satisfaction	Mode of contact	
	Telephone	<i>LiveHelp</i>
Total	†	†
Overall satisfaction		
Very satisfied	1.1	3.6
Satisfied	1.1	3.7
Dissatisfied or very dissatisfied.....	0.6	‡
Expectations		
Exceeded.....	5.6	3.2
Met.....	5.8	3.4
Not met	‡	‡
Knowledge of information specialist		
Very knowledgeable	1.1	3.8
Knowledgeable or somewhat knowledgeable.....	1.1	3.8
Not at all knowledgeable.....	0.3	‡
Trust in information		
A lot	0.8	2.4
Somewhat or a little	0.8	‡
Not at all	0.3	‡

†Not applicable; estimate of standard error is not derived because it is based on an estimate of 100 percent.

‡Reporting standards not met; less than 30 unweighted cases in cell.

Table 13a.—Standard errors for the level of satisfaction with CIS contact by effect on level of confidence: 2004

CIS affected users' confidence in:	Very satisfied	Satisfied	Dissatisfied or very dissatisfied
Total.....	118	1.1	0.5
Ability to seek information			
More	1.3	1.3	0.3
Same.....	1.8	1.9	1.3
Understanding causes/risk factors for cancer¹			
More	3.3	3.3	0.2
Same.....	2.7	2.9	1.6
Actively participating in treatment decisions²			
More	2.4	2.4	0.4
Same.....	3.2	3.3	2.5

Table 14a.—Standard errors for CIS users who called for themselves reporting communication with a health professional (n=3,280), by selected characteristics: 2004

User characteristic	Have discussed	Plan to discuss	Do not plan to discuss
Total.....	1.6	1.5	1.4
Diagnosis			
Diagnosed with cancer.....	2.0	2.0	1.5
Not diagnosed with cancer.....	2.0	2.1	2.2
Cancer site/type			
Breast	2.8	2.6	2.5
Lung.....	2.7	4.0	4.6
Prostate.....	4.3	5.0	‡
Colorectal.....	‡	‡	‡
Other cancer site(s).....	3.0	3.0	2.1
Not applicable/no cancer site specified.....	2.9	2.8	3.6
Level of education			
High school or less	2.4	2.5	2.2
Some college	2.5	2.5	2.3
College graduate or higher	2.4	2.7	2.3
Sex			
Female.....	1.9	1.8	1.5
Male	2.7	3.0	2.9
Age			
40 and under.....	3.1	3.2	2.9
41–50	2.9	3.4	2.9
51–60	2.7	3.1	2.9
61 or older	2.0	2.1	2.2
Race/ethnicity			
White, non-Hispanic	1.8	1.9	1.7
African American, non-Hispanic	4.2	4.0	4.3
Hispanic	5.8	5.9	‡
All other races	5.2	6.0	‡

‡Reporting standards not met; less than 30 unweighted cases in cell.

Table 15a.—Standard errors for the percent of CIS users contacting for themselves who received clinical trials information (n=5,530) reporting specific behavior or intention regarding eligibility for clinical trials, by selected characteristics: 2004

User characteristic	Inquired about eligibility to participate in clinical trials	Have not inquired but plan to find out if eligible
Total percent calling for self receiving clinical trials information	3.2	2.7
Diagnosis		
Diagnosed with cancer.....	3.7	3.6
Not diagnosed with cancer.....	4.6	3.9
Level of education		
High school or less	5.5	4.3
Some college	5.4	5.4
College graduate or higher	5.4	5.3
Sex		
Female	3.5	3.3
Male.....	5.2	4.2
Age		
40 and under.....	‡	5.3
41–50	‡	4.9
51–60	6.2	6.5
61 or older	5.2	4.6
Race/ethnicity		
White, non-Hispanic	3.8	3.1
African American, non-Hispanic	‡	8.6
Hispanic	‡	‡
All other races	‡	‡

‡Reporting standards not met; less than 30 unweighted cases in cell.

Table 16a.—Standard errors for percent of CIS users contacting for themselves and receiving information about clinical trials (n=8,040) who sought more information about clinical trials due to CIS contact: 2004

User characteristic	Percent
Total.....	0.7
Cancer site/type	
Breast	3.8
Lung.....	4.3
Prostate.....	5.6
Colorectal.....	‡
Other cancer site(s).....	5.7
Not applicable/no cancer site specified.....	3.9
Level of education	
High school or less	3.3
Some college	3.2
College graduate or higher	3.3
Sex	
Female	2.4
Male.....	3.4
Age*	
40 and under.....	3.9
41–50	4.7
51–60	4.0
61 or older	3.3
Race/ethnicity	
White, non-Hispanic	2.2
African American, non-Hispanic	5.2
Hispanic	‡
All other races	‡

‡Reporting standards not met; less than 30 unweighted cases in cell.

